Furthering Cancer Education in Nova Scotia:

Interdisciplinary Focus Groups

Final Report

February 2003

Cancer Care
Nova Scotia

DALHOUSIE
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Interdisciplinary Focus Groups

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If you wish to receive the Community Detailed Report (Appendix G) and the Tertiary Care Detailed Report (Appendix H), please contact:

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EXECUTIVE SUMMARY

Cancer Care Nova Scotia (*CCNS*) has recently undertaken a number of collaborative initiatives involving patients and health care professionals, to identify and respond to issues in the provision of cancer care in Nova Scotia. These included comprehensive profession-specific needs assessments to assess the learning and support needs of Nova Scotia family physicians, community specialists, nurses and pharmacists. The final stage was to conduct interdisciplinary focus groups to further explore educational needs in each of the nine district health authorities and the three tertiary care cancer centres. The Dalhousie University Office of Continuing Medical Education (CME) contracted with *CCNS* to conduct these focus groups.

The overall objective of these focus groups was to determine the educational priorities of the physicians, nurses, pharmacists and other health professionals working in each district health authority and the three cancer centres.

Conclusions

Findings of the 10 community focus groups and three tertiary care centre focus groups supported similar themes. Conclusions included the following:

Educational needs of community health professionals

Prominent learning needs, as identified by community professionals themselves and supported by perceptions of the tertiary care health professionals, included:

1. *Treatment and follow-up care, including pain and symptom management.* This need was strongly and extensively expressed across all groups and disciplines. Community health professionals need knowledge of their patients' (both adults and children) treatments and anticipated side effects, practice guidelines for continuing care and, particularly, knowledge of appropriate pain and symptom management measures. Specific educational needs identified were:

   a. Treatment
   - The latest and most effective treatments; i.e., "We need someone to tell us…"this is what's current, this is what we know, this is what you can do""
   - Knowledge of and access to treatment guidelines, treatment protocols and standards of care;
   - Chemotherapy and treatment of its side effects, including appropriate medications; and
   - Lines & pumps – caring for portacaths, PICC lines, Hickman lines and CADD pumps.

   b. Pain and symptom management, encompassing cancer symptoms, management of side effects and palliative care; e.g.:
   - Pain management in treatment, follow-up and palliative care;
   - Changing physicians' ordering practices and improving nursing approaches;
   - Increased knowledge of pain and other medications (e.g., anti-emetics and "magic mouthwashes"); and
   - Nutrition information, especially to assist in counselling patients with disease symptoms or treatment side effects.

   c. Complimentary & alternative therapies - knowledge about the different types of therapies, their pros and cons, and nutritional aspects.

2. *Available resources and supports and how to access them for patient care.* Every focus group highlighted knowledge gaps concerning resources for patients. These included both resources available at the tertiary care centre and in the patient's community, and provincial and national resources, such as the toll-free Canadian Cancer Society information line.

3. *Teamwork: Roles and responsibilities of other members of the team.* This includes knowledge of other team members' expertise and how they can contribute to cancer patient care, both within communities and tertiary care centres. This need was expressed across all disciplines.

4. *Patients' navigating the system.* This is an understanding by health professionals of the cancer care system and how patients have to navigate it, so that community health professionals can provide them with appropriate information and support. Especially important is an understanding of patients' treatment 'road map' and their experience at the cancer centre.

5. *Psychosocial care and patient communication.* All groups discussed aspects of psycho-social care and identified learning needs related to understanding the patients' needs and emotional responses, and being able to communicate appropriately and provide emotional support.

Educational needs of tertiary care health professionals
Prominent learning needs, as identified by tertiary care health professionals themselves included:

1. *Cancer treatment.* The most prominent educational need, based on the discussion data of the three groups, was keeping current with up-to-date information about cancer treatment, and maintaining clinical expertise. For the pediatric centre, maintaining membership with the Children's Oncology Network (COG) was critical in this regard.

2. *Teamwork: Roles and responsibilities of other members of the team.* A better understanding of teamwork was an important educational issue expressed among the groups. This includes understanding other team members' disciplinary roles and responsibilities, and how to effectively communicate with them. This knowledge was perceived to be important for facilitating patient care in terms of knowing "who the resources are" within some participants' own institution and/or in the community.

3. *Awareness of community resources.* Knowledge of community resources to facilitate patient and/or family access to supports when they return home (e.g. financial and psychosocial) was another tertiary centre educational need, expressed in two groups.

Role of tertiary care centres
All three groups indicated that the tertiary centres play three main roles: providing, directing/guiding and ensuring up to date treatment; being a resource, and providing education. Another role, related to the centre's overall treatment role was linking patients with their home community or other parts of the treatment spectrum.

Meeting educational needs in the community
Methods and strategies for meeting the educational needs of the community were discussed by the community health professionals. Tertiary care health professionals commented on their role in meeting these needs. The suggested methods included:

1. *Short, local sessions.* All groups and disciplines expressed a strong preference for short sessions, delivered locally and/or regionally and planned with sensitivity to local conditions. Some participants also indicated that local expertise and resources should be used more frequently.

2. *Case study approaches* received significant attention and positive appraisal from some groups and disciplines. Case study methods are beneficial due to their adaptability to many delivery mechanisms and formats, including print resources, inservices, study groups, the Internet, Telehealth, and workshops. Also, they are ideal for interdisciplinary sessions.

3. There was no clear preference regarding distance *continuing education delivery mechanisms. Telehealth* and the *Internet* received mixed reviews. Telehealth, while improving access was perceived to have at least two limitations: videotaping restrictions and a reduced amount of interaction. Some participants viewed the Internet as a means to more easily access protocols and guidelines.

4. *Interdisciplinary continuing education* appeared to be endorsed in principle by some participants, but its acceptability would depend to some extent on the topic. Palliative care emerged most clearly as a suitable topic for interdisciplinary education.

5. The tertiary care health professionals expressed an overall willingness to serve as a *treatment resource and provide education* for health care providers in the communities. Participants identified some strategies for reaching out to the community, these included Telehealth and 'traveling teams' or 'road shows'.

Systemic issues and barriers in continuing education and cancer care

All groups and disciplines indicated that significant issues and barriers impede their ability to provide optimum care and participate in continuing education programs. These include:

1. *Communication between the communities and cancer treatment centres.* Communication issues were identified in all but one community focus group. Poor flow of information from the cancer centre regarding the patient's condition and treatment, including untimely reports was noted by a number of participants. Delays, duplication or missed follow-up were described as impacts. Sometimes community physicians and other health professionals have to rely on the patient for information. Also, the need for clearer guidelines was expressed, regarding who checks what, when and how.

2. The inter-related systemic issues of *funding, human resource and time limitations* (i.e., lack of coverage, loss of income for physicians and lack of paid educational leave for salaried health care workers) were identified as barriers to both patient care and continuing education.

3. The *financial burden of cancer care to patients* was of concern in several groups. Inadequate financial coverage for medications was emphasized.

4. To reduce the barriers that impede patients' access to care, some suggested providing chemotherapy and follow-up services closer to home.

Recommendations

Conclusions derived from the interdisciplinary focus groups reflect those resulting from the profession-specific needs assessment surveys reported earlier, for family physicians and community specialists, nurses and pharmacists (see footnote [1]). Hence, recommendations support those arising from these earlier studies, and readers are referred to those reports for complementary and additional data and results. Recommendations are presented under two headings:

1. Educational needs and preferred ways of learning
2. Systemic issues influencing cancer care

Educational needs and preferred ways of learning

Focus group discussions reinforced many of the educational needs identified in the earlier needs assessment studies, and recommendations are consistent with those. It is recommended that their implementation be guided by the *CCNS* Education Advisory Group.

1. For community health professionals begin to develop and implement programs that address the priority learning needs identified in the conclusions (refer to conclusion #1 for the community health professionals). These included treatment and follow-up care including pain and symptom management and complementary and alternative therapies, patients' navigation of the system, available resources and supports, teamwork, psycho-social care and patient communication.

2. Begin to respond to the more specialized learning needs of tertiary care health professionals:
    - Cancer treatment: Keeping as current as tertiary care providers.
    - Teamwork: Roles and responsibilities of and effective communication with other members of the health care team.

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[1] The complete Physicians, Nurses, and Pharmacists Needs Assessment reports are available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

- Community resources: Knowing what's available for patients when they return home.

3. Implement educational programs and supports using the preferred methods:
   - Use short, local programs
   - Use case studies as they can be adapted to many teaching formats; e.g., face-to-face sessions, videoconferencing, Internet, self-study.
   - Further explore using telehealth / videoconferencing and the Internet for educational programs.
   - Explore using interdisciplinary approaches to education for appropriate topics; e.g., palliative care, communication, pain and symptom management.

Systemic issues influencing cancer care.
Although systemic issues were not the focus of the discussions, each group addressed them and identified them as priorities for improving both cancer care and cancer care education. (Several are also identified as learning needs in the preceding section, "Educational needs".)

1. Respond to gaps and inefficiencies in communication and information-sharing among members of the health care team, with particular emphasis upon increasing communication between tertiary care centres and community health professionals. (It is recognized that the three tertiary care centres differ with respect to the extent of this problem, and readers are referred to the full text of the two focus group reports for more detail.) (see footnote [2])
   a. Establish an interdisciplinary collaborative working group representative of tertiary care health professionals (oncologists, nurse, pharmacists, etc), community health professional (family physicians, community specialists, nurses, pharmacists, etc) and patients to:
      - Explore gaps in communication addressed in the *CCNS* needs assessment studies, clarify issues and perspectives, recommend strategies, coordinate and oversee their implementation, and monitor and evaluate progress using a quality improvement model.
      - Explore specific options for enhancing communication among tertiary care and community health professionals, such as ensuring that community physicians are represented on *CCNS* site teams, using "checklists' or other simple communication tools when patients return to the community.
      - As part of this work, identify, clarify and educate all members of the cancer care team about the respective roles and skills of team members.

   b. Respond to patients' difficulties in navigating the cancer care system and to the lack of health professionals' knowledge about their patient's cancer care journey. The latter prevents them from supporting patients adequately during their cancer care.
      - Explore options related to developing a patient "roadmap" or "journey map" which would identify the steps involved in each individual patient's "journey" and the health care professionals involved and their roles. This model could be tested and evaluated in one district.

   c. Designate one staff person, knowledgeable about the health care system and cancer care, to guide the processes identified above related to communication among the health care team. This is a large task, and may require hiring or contracting an additional staff person.

2. Increase awareness of and access to resources for both tertiary care and community cancer care health professionals and their patients. This also includes resources available both through the community and in tertiary care centres.

3. Address, as possible, systemic barriers to continuing education – insufficient staffing, insufficient time and lack of financial support for education.

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[2] The complete Community Detailed Report (Appendix G) and the Tertiary Care Detailed Report (Appendix H) are available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

INTRODUCTION

Cancer Care Nova Scotia (*CCNS*) has recently undertaken a number of collaborative initiatives involving patients and health care professionals, to identify and respond to issues in the provision of cancer care in Nova Scotia. This included comprehensive profession-specific needs assessments to assess the learning and support needs of Nova Scotia family physicians, community specialists, nurses and pharmacists. The final stage was to conduct interdisciplinary focus groups to further explore educational needs in each of the nine district health authorities and the three tertiary care cancer centres. The Dalhousie University Office of Continuing Medical Education (CME) contracted with *CCNS* to conduct these focus groups.

The overall objective of these focus groups was to determine the educational priorities of the physicians, nurses, pharmacists and other health professionals working in each district health authority and the three cancer centres.

Specific objectives included the following:
Community focus groups:

1. Discuss how *CCNS* can work most effectively with physicians, nurses, pharmacists and other health professionals to promote interdisciplinary educational opportunities.
2. Identify cancer care and education issues that are unique to each particular district.
3. Examine cancer care community resources within each district and decide how to improve utilization of these resources.
4. Determine the educational priorities of the physicians, nurses, pharmacists and other health professionals working in each district health authority.
5. Examine the District Cancer Program and preferred leadership model for this program.

Tertiary care focus groups:

1. Discuss health care professionals' perceptions of the role of the tertiary care cancer centres in relation to the districts.
2. Identify the educational needs and priorities of physicians, nurses, pharmacists and other health professionals working in the tertiary care cancer centres.
3. Identify cancer centre staff's perspective of the educational needs and priorities of physicians, nurses, pharmacists and other health professionals who provide cancer care in the community.
4. Discuss the role of the tertiary care cancer centres in meeting the educational needs of the communities. Identify the resources and supports required to meet these needs.
5. Discuss how *CCNS* can work most effectively with physicians, nurses, pharmacists and other health professionals to promote interdisciplinary educational opportunities.

METHODS

The following methods were used to design the focus group questions, recruit participants, conduct the focus groups and analyze the data.

1. Development of questions:

Community focus group questions

The focus group questions were developed based on the findings of the family physician and community specialists needs assessments, and oncologists interviews, by the Dalhousie CME Director of Program Development & Evaluation and the CME Research Associate. Modifications were made based on feedback from the *CCNS* Education Coordinator.

The original interview guide attempted to elicit data on several important, often complex topics and was somewhat lengthy. After the first two groups, the format was changed in two ways. The first was to include a nominal group process to increase the emphasis on continuing education needs and learning preferences, and decrease the emphasis on issues and barriers in providing cancer care in the districts. Secondly, the original question guide included items on a proposed leadership model for district cancer care programs and the use of a part-time medical coordinator. Questions pertaining to this area were removed from the guide, when it was found that participants in the first four groups, with a few exceptions, were generally not familiar with the proposed model. (see Appendix A for the final version of the community focus group questions).

Tertiary care focus group questions

Tertiary care focus group questions were developed from the findings of the family physicians and community specialists needs assessments, oncologists interviews and preliminary results from the community focus groups. (see Appendix B for the tertiary care focus group questions)

2. Recruitment Strategy:

Community focus groups

The goal was to conduct 10 focus groups, 1 in each of the 9 district health authorities and 2 in the Capital Health, each with 10-12 participants consisting of approximately 2 specialist physicians, 2 family physicians, 4 nurses (2 with oncology and/or palliative care expertise), 1 pharmacist and 3 other health professionals (i.e., social work, occupational therapy, etc.).

The following recruitment strategies were used with each health profession:

Physicians:

1. In the spring of 2001, a *CCNS* needs assessment questionnaire was sent to approximately 50% of Nova Scotia physicians and community specialists. In addition to the questionnaire, physicians were notified that *CCNS* would be conducting district focus groups to explore learning needs with respect to cancer care. Physicians were asked to indicate whether or not they were interested in participating in a focus group by returning the form. All respondents who said "yes" or "unsure" about participating (family physicians: yes=31 and unsure=28; specialists: yes=15, unsure=10) were mailed a focus group invitation letter.

2. Since the number of physician volunteers was low in some districts, the following methods were also used to recruit family physicians and specialists in these districts:
    a. Invitation letters were mailed to family physicians and specialists in the targeted district health authorities, who had not been sent the *CCNS* questionnaire.
    b. The research team targeted a few family physicians & specialists, known to them, in districts where there were insufficient volunteers. For example, in these districts a member of the research team phoned physicians affiliated with *CCNS* or Dalhousie CME to invite them and/or ask them for suggestions of additional physicians to invite.

Nurses:
A *CCNS* nurses needs assessment was sent to all nurses with oncology and/or palliative care expertise, that were registered with the College of Registered Nurses of Nova Scotia (CRNNS) or found in the *CCNS* list of palliative care nurses. Additionally, questionnaires were sent to a random sample of all other nurses in each district health authority from the CRNNS database. Similar to the procedure described above for physicians, nurses also received information about the upcoming focus groups and were asked to indicate if they were willing to participate. Nurses who expressed interest in the focus groups were mailed an invitation letter with a choice of two dates for their district focus group. All volunteers available on the date chosen were invited to participate unless there were too many volunteers for a particular district. In this case, the nurses were randomly selected from the list of volunteers.

Pharmacists:
CCNS mailed letters to all pharmacists listed in the *CCNS* database to inform them of the upcoming focus group in their district and determine who was interested in participating. One pharmacist per district, available on the date scheduled, was randomly selected from the volunteers.

Other Health Care Professionals:
Names of other health professionals (i.e., social workers, radiation therapists, etc) were obtained from the *CCNS* database containing people who have attended *CCNS* events or been on various *CCNS* committees. Letters were mailed to these people to inform them of the upcoming focus group and to determine who was interested in participating. Up to 3 other health care professionals per district, available on the date scheduled, were randomly selected from the volunteers.

Overall, approximately 80 to 100 health care professionals were invited to participate in each district focus group. On average, 20-25 people volunteered for each.

Tertiary care focus groups
The goal was to conduct three tertiary care focus groups, one at each of the Nova Scotia Tertiary Care Centres: Queen Elizabeth II Health Sciences Centre (QEII), IWK Health Centre (IWK) and Cape Breton Cancer Centre, each with 10-12 participants representing health care professionals involved in patient cancer care (i.e., physicians, nurses, etc.).

Recruitment for these groups varied somewhat for each centre. In Cape Breton, based on the recommendation of the former director of the Cape Breton Cancer Center, members of the hospital accreditation team were invited. At the QEII, all staff at the Cancer Care program were invited. Additionally, nurses who indicated on the nursing needs assessment that they work in one of the Capital Health tertiary care centres were invited. And, at the IWK, all the core members of the Pediatric Cancer Team were invited to participate.

Overall, approximately 15-20 health care professionals were invited to participate in each tertiary care focus group. On average, 10-12 people volunteered for each.

3. Focus groups: Obtaining consent, focus group procedure, and nominal group technique:

Obtaining consent
All focus group volunteers were faxed or mailed a consent form. They were instructed to read the consent form and contact the CME research associate if they had any questions. Volunteers were then asked to sign the consent form and fax it back to *CCNS* if they were willing to participate.

Upon receipt of the signed consent form, participants were faxed information about the focus group logistics for their district (i.e., date, time, location) and a copy of the focus group questions, without prompts.

Demographic questionnaire
A 1-page demographic questionnaire (see Appendix C) was distributed to each participant at the focus group meeting. Participants were instructed to complete the questionnaire and return it to the facilitators after the focus group.

Focus group procedure
There were two facilitators at each focus group, one representative from Dalhousie CME (either the Director of Program Development & Evaluation or the Research Associate) and one from *CCNS* (the Education Coordinator). The Dalhousie CME facilitator was the primary person to ask the series of questions, ensure that all professional groups partook in the discussion, and summarize thoughts/key points at the end of each question. The role of the *CCNS* Education Coordinator was to take notes throughout the discussion, record key points on flip charts, help summarize key points and answer questions.

Each focus group began with the standardized introduction. Participants were welcomed and thanked for their participation. The purpose and objectives of the focus group and the overall needs assessment were explained. Then, the focus group "ground rules" were explained, participants were informed that the focus group was audiotaped and that their responses were confidential.

Focus group questions were designed so that general open-ended questions were asked first to facilitate discussion from all participants (i.e., what is your role in caring for cancer patients), then became progressively more focused on the topics of interest.

In the first 2 focus groups, participants spent a great deal of time discussing systemic and patient education issues that affected their ability to provide optimal care and participate in continuing education, rather than discussing their educational needs and priorities. In an attempt to minimize discussion of these topics and maximize the time spent discussing educational issues, the format was modified in two ways. First, for the remaining groups, the facilitators reviewed and discussed barriers and system issues at the beginning of the focus group. Participants were asked if system factors (i.e., time, money, etc.) were issues in their community. They were also asked to indicate if there were any issues specific to their community (i.e., language barriers) that weren't presented on the prepared flip chart sheet. Once these issues were discussed, participants were asked to refrain from discussing these issues until near the end of the focus group. Secondly, a nominal group technique was added to the format to ensure that the discussion focused on educational needs and priorities.

After the educational needs and priorities were identified and discussed, the focus group procedure was resumed to discuss the remaining topics (i.e., preferred learning methods and attitudes towards interdisciplinary learning).

Nominal group technique
Participants were given a worksheet (see Appendix D) and were asked to spend 5 minutes writing down a minimum of three educational needs, related to cancer care, for themselves and other health care professionals. They were also asked to indicate on the worksheet which health care professionals needed education in each area. Participants in the tertiary groups were asked to identify their own needs and the needs of community health care professionals.

At the end of 5 minutes, participants took turns identifying their educational needs. Only one need was reported at a time, to ensure that everyone had an opportunity to contribute. Some discussion took place during this process to clarify, elaborate and illustrate the educational needs. This continued until all topics were identified and recorded on the flip chart.

Once all the educational needs were recorded, participants were asked to review them to ensure that they understood each and nothing was omitted. Also, participants were asked to indicate if any of the needs should be combined, i.e. if 2 or more were saying the same thing.

The next step was for participants to prioritize the identified educational needs. Community focus group participants were given 5 coloured stickers to put beside the 5 educational needs that each felt were the priorities. Tertiary care participants were each given six stickers to prioritize the top three educational needs for themselves and for health care professionals in the community. Stickers were colour coded by profession (i.e. yellow stickers for physicians, green for nurses, etc.).

4. Analysis: Questionnaire, focus group, nominal group technique and worksheet:

Demographic questionnaire

Descriptive statistics, including means, frequencies, and percentages were calculated for each item using the software SPSS 10.1 for Windows (SPSS Inc., Chicago, IL). Results from the questionnaire are reported in the participants' section.

Qualitative Analysis of Focus Groups

Transcripts of the taped focus groups were verified by the analyst before importing into NUD*IST 4[1] for data management. When necessary, a facilitator was consulted to interpret any potentially significant portions that were unclearly taped and incompletely transcribed.

Data were systematically coded; that is, broken down into meaningful units and assigned to categories in 'index trees' that were initially structured according to interview guide and developed further as new categories emerged from the data. A constant comparative approach[2, 3] (e.g. within and between categories of data) was used in the interpretation, aided by matrices[4] constructed to facilitate comparisons within and between disciplines and districts or centres. Negative cases (instances that did not appear to fit patterns in the data) were identified, and alternative explanations were considered.[5] Themes were identified and interpreted.[5] Findings were further synthesized in the report writing process.

Several measures were employed in the analysis to ensure credibility and trustworthiness of the qualitative findings.[6, 7] A systematic analytic approach was used, as previously described. An audit trail comprised of the transcripts, coding reports and matrices permits confirmation that the findings arise from the data. Analysis was conducted by a person with a health and adult education background, and experienced in qualitative research. Credibility was further enhanced through review of findings by the three group facilitators/observers. For the tertiary care focus groups, developing interpretations were checked and further refined through discussions with one facilitator.

Nominal group technique & worksheet

The nominal group technique was used with 8 of the 10 community focus groups and the 3 tertiary care groups. The educational needs identified for each group were recorded into tables for each district. To ensure that every participant's needs had been identified during the nominal group process, the worksheets were carefully reviewed and compared to the flip chart results. Needs that were identified on the worksheets but omitted during the nominal group process were added to the districts' summary table.

To determine the educational priorities for each district, the frequency of stickers overall and by profession were calculated. These needs were then categorized according to the area of the cancer spectrum that they addressed (i.e., prevention, screening, diagnosis, treatment, palliative care or follow-up) and ranked accordingly.

RESULTS

Results are reported separately for the community and tertiary care focus groups. First the participants are described and then the group findings. Please see Appendices E and F for the prioritized nominal group results categorized by district and tertiary care centre, and Appendices G and H for community and tertiary care detailed reports. (see footnote [3])

SECTION 1: Community Focus Group Results

Multidisciplinary focus groups were held in the 9 Nova Scotia district health authorities (two groups were held in Capital Health), between April and June 2002.

Participants:
A total of 98 health care providers participated in 10 multidisciplinary focus groups, each approximately two hours in length. The 1-page demographic questionnaire was completed by 92 of these participants, 15% of whom were male and 85% were female.

Nurses (44), physicians (18) and pharmacists (14) comprised 78% of participants overall, with the 22 remaining participants from 8 other disciplines (see Table 1). Overall, there were 8 community-based specialists and 10 general practitioners or family physicians. The number of years that participants had been practicing in their profession ranged from 0 to 44 years, with a mean of 21 years in practice. Two of the family physicians had special interest in palliative care. The nurses practiced in a variety of settings, including ambulatory care (chemotherapy and diagnostic services), acute care, palliative care, home care, the community and long-term care. Community (retail) and hospital pharmacists also attended. Thirty- seven percent (37%) of participants indicated that they have specialized training in oncology or palliative care. Ten percent (10%) of participants indicated they had interest in cancer care aside from their immediate health care provider role. Four participants disclosed personal or close family experience with the cancer care system, and seven were active as volunteers (health care, cancer care, and palliative care related governing boards or in volunteer roles involving direct cancer patient or public contact). One participant was a lay person active at the board level in the voluntary sector.

Table 1: Total number of community participants by health care affiliation.

Professional Affiliation	No.
Physician	18
Nurse	44
Pharmacist	14
Dietitian	6
Social Work	6
Spiritual Care/Chaplain	2
Volunteer Coordinator	2
Technologist	2
Other	4*
TOTAL	98

*includes physiotherapy, management and volunteer

As shown in Table 2, the majority of participants see cancer patients on a regular basis. Only 5.6% reported that they didn't see any cancer patients over the last 3 months.

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[3] The complete Community Detailed Report (Appendix G) and the Tertiary Care Detailed Report (Appendix H) are available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

Table 2: Frequency of cancer patients seen by community participants over the past 3 months.

Number of patients with cancer over the last 3 months	No.	Percent
0	5	5.6
1-5	18	20.2
6-10	16	18.0
> 10	50	56.2

Group Composition & Size

All groups were multidisciplinary, with six groups containing five different disciplines, and four groups containing four disciplines. Nine of ten groups contained at least one physician, with 6 groups having two or more. As shown in Table 3, professional practice settings differed by health profession and district. Also, many participants indicated that they work in more than one practice setting.

Table 3: Practice settings of the community focus group participants.

	District (frequency)									**Overall**
Practice Setting	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**(n)**
Private Office	0	3	2	0	2	3	1	2	3	16
Regional or District Hospital	4	7	5	3	5	5	3	5	6	43
Tertiary Care Hospital	0	0	0	0	0	0	0	0	4	4
Small Community Hospital	3	1	0	1	3	0	3	0	3	14
Clinic	1	0	0	0	0	0	0	1	1	3
Home care program/agency	2	1	0	4	2	1	0	1	1	12
Nursing home/long term care	0	0	2	0	2	1	1	0	2	8
Community Health Agency	0	0	0	0	1	1	0	1	0	3
Other	3	2	2	0	0	2	1	2	2	14

As shown in Table 4, groups ranged in size from 6 to 13 participants, with 6 groups having 10 or more participants. The number of participants was appropriate for the nominal group process but was likely too large for optimum use of the focus group method. Groups of 6-10 participants are recommended[2] to allow participants adequate opportunity to discuss topics.

Table 4: Total Number of Focus Group Participants from each Health District.

Health District	No.
South Shore District Health Authority (District 1)	12
Southwest Nova District Health Authority (District 2)	12
Annapolis Valley Health (District 3)	13
Colchester East Hants Health Authority (District 4)	7
Cumberland Health Authority (District 5)	11
Pictou County Health Authority (District 6)	10
Guysborough Antigonish Strait Health Authority (District 7)	7
Cape Breton District Health Authority (District 8)	10
Capital Health (District 9) – June 5th	9
Capital Health (District 9) – June 13th	6

Focus group findings:
Four overall topics were explored in the community focus groups:

1. Educational needs and preferences
2. Meeting educational needs
3. Systemic issues
4. Awareness of District Cancer Program

Please refer to the complete report in Appendix G (see footnote [4]) for a comprehensive discussion of these topics.

1. Educational needs and preferences

Data analyses of the nominal group process and group discussion were combined to determine educational needs. The following sections report results predominantly from the discussion analysis, while results of the nominal group process are included in the section "Educational priorities", page 22.

The prominent learning needs were:

1.1 Treatment and follow-up care, including pain and symptom management
1.2 Patients' navigating the system
1.3 Available resources and support
1.4 Teamwork: Roles and responsibilities of other members of the team
1.5 Psychosocial care and patient communication

Also discussed are:

1.6 Other learning needs
1.7 Educational priorities from nominal group process

The educational themes are captured by this participant's comments:

> "I would I think, I as a physician, need to be educated by specialists who are doing that kind of work as to what the new treatments are, what's appropriate, when to do this and when to do that. But at the same time, I'm lost when it comes to knowing, you know, what's available in the community. What's available to people who have cancer, who you're working with and how you're going to either…so there's a whole big education there that we have to…I think, for physicians to understand we're part of a team and we need to know who's on the team" (physician)

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[4] The complete Community Detailed Report (Appendix G) is available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

1.1 Treatment and follow-up care, including pain & symptom management

Education on current cancer treatment, including pain and symptom management, was a strongly voiced need, extensively expressed among disciplines and groups. Some participants recognized a need for both themselves and their colleagues to update their knowledge concerning the current, most effective treatments. Physicians, both specialists and general practitioners, nurses in many practice settings, and pharmacists spoke of needing to update their knowledge, as treatments have advanced and changed. Participants described how knowledge of treatments and their side effects is a prerequisite to providing not only the best medical treatment and follow-up, but also to providing skilled physical and psychosocial supportive care in all stages of cancer care, including palliative care. Adequate, applicable current knowledge is needed to deal with cancer patients' problems at the district level where specialized resources are limited (e.g. treatment of emergent treatment complications, managing nutrition related side effects in chemotherapy patients).

While the extent of knowledge required may vary among the disciplines according to their roles, information about current treatment and its related aspects was a widespread need.

Specialists and some pharmacists stressed the need for treatment and/or follow up guidelines and protocols. The Internet was viewed by some physicians, pharmacists and nurses as a way to improve access to guidelines and/or protocols.

Topics of highest need interest across several disciplines included:

- Treatment:
    - The latest and most effective treatments; i.e., "We need someone to tell us…"this is what's current, this is what we know, this is what you can do""
    - Knowledge of and access to treatment guidelines, treatment protocols and standards of care;
    - Chemotherapy and treatment of its side effects, including appropriate medications; and
    - Lines & pumps – caring for portacaths, PICC lines, Hickman lines and CADD pumps.

- Pain and symptom management, encompassing cancer symptoms, management of side effects and palliative care:
    - Pain management in treatment, follow-up and palliative care;
    - Changing physicians' ordering practices and improving nursing approaches;
    - Increased knowledge of pain and other medications (e.g., anti-emetics and "magic mouthwashes"); and
    - Nutrition information, especially to assist in counselling patients with disease symptoms or treatment side effects.

- Other:
    - Complimentary & alternative therapies - knowledge about the different types of therapies, their pros and cons, and nutritional aspects.

1.2 Patients' navigating the system

Discussion occurred in all ten groups concerning various aspects of patients and professionals 'navigating' the cancer care treatment system. Professionals from several disciplines described how patients feel "overwhelmed," are anxious, do not know or understand what will happen next, and have many questions that front line professionals are sometimes unable to answer. Learning needs with respect to navigating the cancer care system emerged, and focused on understanding both the patient's treatment and their cancer centre experience.

This included an understanding of the patient's treatment 'road map' and their experience at the cancer centre. 'Understanding What's Ahead for Them' was a theme expressed in several groups. Professionals across many disciplines articulated that they need a better understanding of the cancer treatment and the cancer centre experience to be able to answer some of their patients' questions, and direct the patient to appropriate resources, both at the cancer treatment centre and locally. As one community pharmacist said, "you become the navigator because nobody else is available".

Support for the navigator position or concept was evident in several districts, as a resource for patients, families, and health care providers, and serving as a link to the cancer treatment centre. (Note: *CCNS*, as the result of comprehensive consultation of patients and health professionals, has identified patient navigation as a priority and has put in place patient navigator positions in three districts, as early-adopter or pilot sites.)

1.3 Available resources and supports

All focus groups highlighted the need for health care providers to know about available resources and how to access them. This was a prominent need, extensively expressed among physicians, nurses, social workers and community pharmacists. Some participants clearly articulated that they want to be able to direct patients to community resources and services, but lack the information to do so. Variable knowledge appeared to exist in some groups about the toll-free Cancer Information Service, one accessible source of resource information. Some participants commented on the need for more knowledge about regional and district resources both at the local community level and at the cancer treatment centre level.

1.4 Teamwork: Roles and responsibilities of other members of the team

Most groups discussed various aspects of teamwork, such as knowing more about other team members' roles, and the value of and need for improved team communication. There was broad interest in what other professionals know, and how their expertise contributes to patient care. This was expressed across several disciplines, and often by physicians.

> "I think everybody on the team needs to have a flavour of the other disciplines, I mean it's part of the education, it's part of the team building process. So I know what your role is, you now what my role is, but I also know when I see a patient at home on this drug that 'oh, there may be a couple things going on,' so I come back and tell the right people." (nurse)

Refer to systemic issues, page 25, for additional discussion related to this topic.

1.5 Psycho-social care and patient communication

All groups discussed aspects of psycho-social care, and learning needs include understanding the patients' needs and emotional responses and being able to provide support. These aspects of care incorporate both knowledge and communication skills, as described in this comment:

> "See from my point of view as a doc in the community, I would see a role for myself and with my patient, in trying to interpret some of that for my patients and maybe providing some of that touchy-feely stuff that you don't get at the clinic. But I can't do that if I don't know what the hell is going on!" (general practitioner)

Specific communication needs identified were conveying bad news (e.g., cancer diagnosis or prognosis) and discussing end of life issues (e.g., palliative care decisions, living wills, power of attorney, etc.).

1.6 Other learning needs

Some groups raised learning needs related to Prevention, Screening and Diagnosis, but these were not discussed across all groups, as were the above topics. Although not as prominent, they were important to some participants and their perspectives are contained in the full report.

1.7 Educational priorities identified by the nominal group technique

The nominal group prioritizing exercise reinforced the educational needs identified through the focus group discussion process. Table 5 shows the top 3 priorities identified in the 8 focus groups that participated in the nominal group process. Note, South Shore District and Colchester East Hants Health Authories are not included as this process was not used with them.

In summary, the nominal group process showed that the educational priorities for most districts included: treatment and follow-up, knowledge of available resources, and improved interprofessional communication skills. Specific skills identified by each district are listed in Appendix E.

Table 5: Top three educational priorities for each district health authority.

District	Priority #1	Priority #2	Priority #3
Southwest Nova	**Treatment & follow-up** - nausea & vomiting - best practices - expectations	**Available resources** - services available? - who does what?	**Interdisciplinary communication** - sharing information amongst team - working as a team
Annapolis Valley	**Treatment & follow-up** - current standards & guidelines - pain management	**Prevention** - Patient & public education	**Available resources** - services available?
Cumberland	**Treatment & follow-up** - oncology therapeutics - standards of care	**Palliative Care** - change standards in long term care - increase comfort with dying patients	**Available resources** - continuity of services available - services available?
Pictou County	**Treatment & follow-up** - knowledge of chemotherapy drugs & side effects	**Patient/family communication** - giving diagnosis & discussing dying	**Prevention & Screening** - guidance based guidelines - education of public & health professionals
Guysborough Antigonish Strait	**Treatment & follow-up** - standards of care, procedures & techniques	**Interdisciplinary communication** - improved communication between hospital & community	**Available resources** - services available? - patient navigator could be a liaison
Cape Breton	**Interdisciplinary communication** - improve communication with health professionals re patients' cancer journey & new knowledge	**Treatment & follow-up** - treatment options - management & therapies used	**Available resources** - services available?
Capital Health June 5th	**Treatment & follow-up** - info re treatments - pain & symptom management - adverse affects	**Interdisciplinary communication** - work as a team - seamless care - improved communication skills	**Psychosocial care** - understanding emotional needs of patients - cultural & ethnic practices
Capital Health June 13th	**Treatment & follow-up** - alternative therapies - newest diagnostic methods & tests - new treatment	**Interdisciplinary communication** - communication skills with other health providers - team approach to patient care	**Available resources** - services available?

2. Meeting educational needs

Discussions generally supported continuing education (CE) programs that are consistent with adult education principles; i.e.:

- provide opportunity to learn relevant, useful information
- in an environment compatible with their learning styles, and
- facilitate sufficient interaction to meet learners' professional networking and learning needs.

Nine of the ten groups were asked to comment on their preferred learning methods and continuing education formats. Methods or formats were differentially explored across groups and some groups discussed particular methods and formats more than others. Internet use appeared to be probed more systematically. Despite the differences in the discussions, information was gathered about learning methods and formats which appear to be most helpful, particularly in light of barriers to participating in formal continuing education programs.

Participants, providing health care in a context of resource limitations, expressed a strong preference for local/regional delivery of short continuing education sessions. While there appeared to be some support for interdisciplinary education in principle, its acceptability may depend on the topic (e.g. palliative care).

2.1 Short, locally delivered sessions

Many participants across professional groups indicated preferences for short sessions that are held locally and/or regionally and planned with sensitivity to local conditions. This preference was strongly articulated among physicians, but also expressed by other health care providers. While the data presents some factors to consider in determining the best time, duration, and locations for CE, it also suggests further assessment within districts is needed to develop the most acceptable programming.

The demand for short episodes, delivered locally appears related to:

- problems providing coverage of patient care which constrain the participants' ability to attend CE,
- the amount of time available to attend CE, and
- compensation issues, such as loss of income for fee for service providers and paid leave for salaried professionals.

Videotaping and multiple continuing education delivery mechanisms may be required to reach participants given the resource and time constraints.

2.2 Case study format

The extent to which specific formats for continuing education were explored varied among groups. Case study approaches, while not extensively discussed, when they were addressed received significant attention and positive appraisal. First hand reports indicated that even in a simple form (such as a case based scenario accompanying a patient's discharge summary), case study materials facilitated a multidisciplinary approach to care.

The significance of the case study method rests also with its adaptability to a variety of delivery mechanisms and formats, including print resources, inservices, study groups, the Internet, Telehealth and workshops. This is important since no single method received universal support among participants, consistent with the view that different people with different learning styles will prefer different formats.

2.3 Local resources

There was some recognition that local expertise and resources were underused with respect to continuing education. The underlying themes of human resources and time limitations (see 2.6 below) suggest that current capacity to engage local resources in delivering intensive continuing education efforts may be limited. This would need to be explored further at a district or regional level.

2.4 Delivery methods

No clear preference emerged regarding continuing education delivery methods. As a continuing education program delivery method, *the Internet* evoked a mixed reaction, with convenience and level of interaction appearing as some of the factors influencing its acceptability. Its potential use to disseminate standards of care and protocols was evident, although some indicated print resources might be required because of access barriers. Several participants also wanted to be able to direct patients to reliable web sites.

Telehealth also received mixed reviews, with improving access a perceived benefit to some, in the context of geographic and resource constraints. Nurses frequently mentioned videotaping of Telehealth sessions for viewing at more convenient times. Two major limitations surfaced: videotaping restrictions (affecting access to the information) and the degree of interaction Telehealth affords. Data suggested these barriers could be at least partially overcome by centrally located videotaping and skillful facilitation with appropriately sized groups.

2.5 Interdisciplinary Continuing Education

Interdisciplinary Education appeared to be endorsed in principle by some participants, but its acceptability would depend to some extent on the topic. Palliative care was viewed positively and emerged most clearly as a suitable topic for interdisciplinary education. This implies it may be an appropriate model to examine if planning education on other topics. Data suggested the following elements may be important aspects of palliative care interdisciplinary education: a clear patient care focus, a recognized need for shared expertise, and an opportunity for team building incorporated into the educational processes. Other topics were suggested for interdisciplinary education, but there was insufficient data to assess their appeal. They included pain and symptom management, dealing with the patient holistically or as an individual, ethical issues, and community resources. Groups under explored any problems that might exist concerning bringing together the different disciplines.

2.6 Barriers to CE

Participants identified significant resource barriers to continuing education (CE), including insufficient human resources to relieve potential CE participants, the amount of time available to attend, and funding issues such as income loss for physicians and lack of paid educational leave for other health care workers.

3. Systemic issues

While the main purpose of the focus groups was to examine the continuing education needs and learning preferences among health care disciplines in the districts, themes also emerged pertaining to systemic issues in the provision of cancer care. These emerged in spite of efforts by facilitators to re-direct discussions towards educational issues, emphasizing the importance participants placed on the role of systemic issues. Issues identified included working with the cancer treatment centre, human resource and time constraints, financial burden for patients and patient access to cancer care. Participants identified the significant human resource, time and funding barriers that constrain their ability not only to participate in continuing education but also affect the delivery of cancer care at the district level.

3.1 Working with the Cancer Treatment Centre

Communication, coordination and relationship issues with the cancer treatment centre were raised in most groups, and appeared to be an important theme. The words of one nurse participant help to illustrate this:

"…it becomes a specialist's world in terms of care of the oncologists for the patients and the family doctor is often left 'out of the loop' " (nurse)

This concern also builds on the earlier discussion of the education need, "*Teamwork: Roles and responsibilities of other members of the team* page 21. Some participants perceived poor communication and coordination as a system wide issue that also exists at the local level, and not only in the relationship with the cancer treatment centre.

Communication issues with the cancer treatment centre were identified in all but one focus group. While different groups described various aspects of the problem, this concern was extensively and sometimes intensely expressed, sometimes with strong agreement within groups.

Poor flow of information from the centre, including untimely reports, was a significant observation of several physicians, other team members, and members of patients' families. It is also noted that there was one report that information flow has shown improvement. Several impacts of lack of information were described. Sometimes community physicians have to provide urgent care for patients with complications or other medical problems without up-to-date knowledge of the patient's cancer condition and treatment protocol. Sometimes they have to rely on patients for information. Without information and up-to-date knowledge of current treatments, health care providers are sometimes unable to answer patients' questions. Support was expressed in some groups for a patient-carried record as one solution.

Difficulties providing follow-up at the district level were reported, with respect to untimely communication and insufficient communication on treatment protocols and follow-up care.

Lack of coordination with the cancer treatment centre was another identified issue. Coordination problems with respect to follow-up were articulated. Delays, duplication or missed follow-up were described. A 'road map' was suggested, more clearly defining roles and responsibilities in patient follow-up.

There was also a perceived need among some participants for an increased awareness and understanding on the part of the cancer treatment centre with respect to district expertise, the patients' environment, available district resources and their limitations.

Communication, coordination and team work problems have other intangible aspects. Perceived poor communication may contribute to a sense that the patient is "taken over" by the centre, and in some cases, that district level expertise is undervalued.

3.2 Human Resources & Time Constraints

Participants described how human resources and time constraints can pose barriers to treating and caring for patients, affect the implementation of a multidisciplinary approach, and reduce the opportunity to participate in continuing education. Some specific gaps in palliative care services and resources were raised in several groups including resource and policy barriers to delivering palliative care in long term care.

3.3 Financial Burden of Cancer

The financial burden of cancer experienced by patients was another systemic issue of concern to several participants, especially with respect to funding medication coverage for patients at home and those with incomes above the $15,720 cut off.

3.4 Access

Access issues emerged in some groups, especially with respect to geographical barriers and transportation difficulties for older patients and those with lower incomes. Distance and time away from home may be other factors affecting patients' decisions regarding treatment. There was some support for more chemotherapy and follow-up closer to home to relieve patient burden.

4. Awareness of District Cancer Care Program

Findings are restricted to four groups, with three of these groups having opportunity to explore both the overall concept and the medical coordinator role. It is noteworthy that only a few individuals across the four groups indicated some knowledge of the proposed program. In subsequent groups, questions on this topic were eliminated because previous participants were generally unfamiliar with the concept.

4.1 Funding Concerns

Some support for the concept of district cancer care was apparent, both explicitly stated with respect to the topic and implicit in the context of other discussions concerning access to treatment (chemotherapy) and follow-up. However, funding concerns were a predominant theme, with a strong perception that district cancer care will require new funding, that existing budgets and resources cannot accommodate the further strain anticipated with a shifting of cancer care to the districts. There was also concern that districts may be made to assume care without the necessary new resources to make it achievable and with negative impact, i.e. 'shrinking' of existing resources. Lack of support for this approach was evident. One physician's comment seemed to summarize group opinion - "So to talk about district cancer care until the funding issue has been addressed...I think everyone's skeptical that it's going to fly." (physician)

The medical coordinator position was perceived to require new funding. Some questions were raised regarding the role, and the family physician's involvement. Separation of clinical and administrative functions were also recommended.

SECTION 2: Tertiary Care Focus Group Results

Three multidisciplinary, tertiary cancer care centre focus groups were held in June and July 2002. Groups were asked to discuss the role of their centres in relation to the districts and identify and discuss, using a nominal group process, the educational needs of health professionals working at the centres and in the community.

Participants:
A total of 27 health professionals from 12 different disciplines participated (Table 6). The 1-page demographic questionnaire was completed by 25 of these participants, 32% of whom were male and 68% were female. Groups were of equal size, and were remarkable in their heterogeneity both within and between disciplines. Seventy-two (72%) of participants indicated that they had specialized training in oncology or palliative care and 88% of participants reported that they saw over 10 patients with cancer in the last three months (Table 7). Of the four physicians who participated, two identified themselves as oncologists. Nine participants were nurses with experience in a variety of oncology roles, including treatment and palliative care. There were 14 other participants from pharmacy, social work, dietetics, rehabilitation therapy, spiritual care and other specialized areas of cancer care delivery, coordination and administration. The number of years that participants had been practicing in their profession ranged from 2 to 32 years, with a mean of 16.5 years in practice.

Heterogeneity was evident among the groups. One group appeared to be composed of several members associated with care for a particular type of cancer, whereas this was not apparent in the other groups. One group did not contain an oncologist's perspective. Radiation, chemotherapy, pharmacy, and administration, managerial and other specialized disciplinary perspectives were not similarly represented across groups.

Table 6: Total number of tertiary participants by health care affiliation

Professional Affiliation	No.
Physician	4
Nurse	9
Pharmacist	2
Dietitian	1
Social Work	2
Spiritual Care/Chaplain	2
Radiation Therapist	2
Other	5**
TOTAL	27

** includes director of cancer centre, child life specialist, occupational therapist, medical physicist, Atlantic coordinator

Table 7: Frequency of cancer patients seen by tertiary participants over the past 3 months

Number of patients with cancer over the last 3 months	No.	Percent
0	2	8.3
1-5	0	0
6-10	1	4.2
> 10	21	87.5

Focus group findings:

Four general topics were explored in the tertiary focus groups:

1. Role of the tertiary care centres (cancer centres)
2. Educational needs of the cancer centre staff
3. Cancer centre staff's perceptions of learning needs of the community health professionals
4. Meeting educational needs

1. Role of the tertiary care centres (cancer centres)

Three tertiary centre roles emerged as prominent themes in the data:
1.1 Providing, directing/guiding and ensuring up-to-date treatment;
1.2 Being a resource and providing education; and
1.3 Linking patients with their home community or other parts of the treatment spectrum.
The first two roles were expressed in all groups, whereas the third role was explicitly expressed in two groups, with some implicit evidence present in the third group.

1.1 Providing, directing and/or guiding, and ensuring up-to-date treatment

This appeared to be the central role. Support was evident for providing treatment closer to the patient's home when feasible in terms of resources available in the community. The centre's role includes planning treatment and developing or providing protocols and clinical practice guidelines. Knowledge of clinical practice guidelines was a prominent educational need identified for the communities. Physician participants especially described a tertiary centre role in ensuring that up to date treatment is provided based on standards. For pediatric cancer care, participation in the Children's Oncology Network (COG), demands compliance with protocols. In one centre, a physician remarked,

> "I think too, maybe just expanding on what I said earlier, this really applies to all health professions. The most important thing about us a tertiary centre is that we see that optimal standards are applied uniformly across the province, and that 'just ain't happening.' "

1.2 Being a resource and providing education

Participants expressed an overall willingness to serve as a treatment resource and provide education for health care providers in the communities.

> "One thing I think that we need to increase knowledge of the communities of available resources that are here, and that we're not perceived of as the ivory tower, cause I've heard that at times, so that we're perceived as just willing to share and work with the community and to best enable care for the patient and family."

It was expressed in all groups that communities or peripheral centres vary in their resources and capacity to provide treatment. It was also explained that the centre's role as a resource for treatment will vary accordingly, from provision of specific treatments to guidance and consultation.

> "... some facilities are just going to use us as a [treatment] resource, and some facilities can be...educated more thoroughly. But they're not all equal."

1.3 Linking and liaison

There was also evidence expressed in two groups of a linking role, related to the centre's overall treatment role. This involves connecting patients to care in their home community or other areas of the cancer treatment spectrum. Working relationships and communication appeared important in this regard.

2. Educational needs of the cancer centre staff

Data analyses of the nominal group process and group discussion were combined to determine educational needs of the cancer centre staff. The following section reports results predominantly from the discussion analysis, while results of the nominal group process are included in the section "Educational priorities", page 32.

The prominent learning needs were:
2.1 Cancer treatment: Keeping current
2.2 Teamwork; Roles, responsibilities and effective communication
2.3 Community resources
2.4 Other learning needs

Also discussed are:
2.5 Educational priorities for Cancer Care Staff (as identified in the nominal group process)

2.1 Cancer treatment: Keeping current

The most prominent educational need, based on the discussion data of the three groups, appeared to be keeping current with up-to-date cancer treatment. For the pediatric centre, maintaining COG membership was critical in this regard. The role of networking to maintain current knowledge was prominent in a few health professions, especially from the medical, nursing and pharmacy perspectives offered. A broader knowledge base about cancer care was identified as a need by participants from several disciplines.

Detailed information on educational needs related to maintaining clinical expertise was not systematically obtained. Some individuals cited specific educational needs (nutritional assessment, psychotherapeutic counselling techniques, and lymphaedema prevention and treatment), that pertained to their own discipline or their focus on treating particular cancers. Further exploration is necessary to obtain a complete understanding of discipline-specific needs.

2.2 Teamwork: Roles and responsibilities of other members of the team

A better understanding of teamwork, including others' roles and responsibilities and effective communication was an important educational issue expressed among the groups. As one nurse remarked:

> "I think the one very positive thing we could possibly do for ourselves, is that, as much as we espouse multidisciplinary team, interdisciplinary team, most places function loosely as a team, and I think we could do a whole lot around making nice, sharp, cohesive, very patient focused teams. I think we can do something about that."

Understanding other team members' disciplinary roles and responsibilities was a need articulated in two groups. This knowledge was perceived to be important for facilitating patient care in terms of knowing "who the resources are" within some participants' own institution and/or in the community. For example, radiation therapists with frequent, ongoing patient contact might identify problems and refer patients to other team members for assistance, if they were more knowledgeable about others' roles and responsibilities.

Some participants noted a lack of clarity as to who has responsibility for the patient's care. This was raised in the two adult treatment centre groups, and communication may be one contributing factor. Information as to who has responsibility for care may not always be adequately communicated to team members or to the patient, as the following comments help illustrate:

> "And for the patients to know who is directing their care when they leave here, and I mean hopefully the physicians that occurs on their last visit. Who is sort of you know, the main coach in your care? Like is it going to be your family physician, palliative care, cancer centre doctor, like who do you call?"

> This same participant further described, "A lot of times we are getting calls when it should be the family doctor and I think people just don't know who's doing what."

Further, there was a perceived reluctance on the part of family physicians in some instances to reassume care. An array of reasons were offered by both physician and non physician participants in one adult centre group. These included: physicians may feel intimidated related to their lack of knowledge; there are complex issues of patient "ownership; " sometimes family physicians may assume someone else has responsibility once referral is made; and there is inadequate reimbursement for dealing with time consuming problems.

The limited data available suggested that clarifying and understanding roles and responsibilities in patient care is a multifaceted issue. Interestingly, clarity was not raised as a problem in the IWK group, which also described explicit communication between the centre's team members and professionals in the community.

Problems with some communication channels were noted in other groups (e.g. family physicians not reading dictated notes; information not quickly available when responding to calls from palliative care patients at home). Overall, data indicated that communication is both a systemic and educational issue. As one participant summarized, "what we really need to work on [is] on the communication channels and getting people to contact each other."

2.3 Community resources

Knowledge of community resources to facilitate patient and/or family access to supports when they return home (e.g. financial and psychosocial) was another tertiary centre educational need, expressed in two groups. The importance of this need was most extensively discussed in the IWK group in the context of shared interdisciplinary care. This group also noted that sometimes supports or resources are assumed to exist when they in fact do not, and that advocacy for pediatric resources is needed. Also, it was suggested that specialists and family physicians should encourage their patients to use the toll free Cancer Information Service, since some patients may not return to the family physician before their contact with the centre.

2.4 Other learning needs

Other identified needs, less extensively discussed, included *palliative care, patient communication* (conveying bad news and communicating with patients in end stages), *psychosocial, family and spiritual care.*

2.5 Educational priorities of Cancer Care Staff (as identified in the nominal group process)

The nominal group prioritizing exercise reinforced the educational needs identified through the focus group discussion process. The educational priorities for health care professionals working in tertiary care centres are listed below for each of the three cancer centres:

QEII Cancer Care Centre

(1) The majority of participants indicated that they need to increase their knowledge about *treatment & follow-up*. Specific topics identified were: basic oncology information; medical terms, and implications of diagnosis and prognosis on psychosocial aspects of patient's life.
(2) An *increased awareness of the cancer process* and an *understanding of others' roles* were also identified as priorities. Health care professionals indicated that they need a better understanding of the process from diagnosis to treatment to palliative care.

Cape Breton Cancer Centre

(1) *Psycho-social needs* were identified as the educational priority for this group. Specific topics included: recognizing and providing for spiritual needs, giving bad news to patients, and supporting patients after they receive bad news.
(2) *Treatment & follow-up* – focus group participants indicated that more education is needed in the administration and side effects of chemotherapy, and in pain management.

IWK Cancer Centre

(1) *Patient needs and resources*: The top educational priority for this group was an increased awareness and knowledge of patients' home life, family and community, and the resources available in that community to assist them when they return.

(2) *Treatment & follow-up* was also rated as a prominent educational need. This includes keeping current with up-to-date information on the complete spectrum of patient needs (i.e., treatment, diagnosis, psychosocial and supportive care, and oncological emergencies).

3. Cancer centre staff's perceptions of learning needs of the community health professionals

Tertiary care groups were also asked to identify and discuss their perception of the learning needs for community health professionals caring for cancer patients. The prominent learning needs were:

3.1 Treatment and follow-up care, including pain and symptom management
3.2 Knowledge of tertiary centre resources
3.3 Awareness of community resources
3.4 Other learning needs

Also discussed are:
3.5 Cancer Centre staff's perceptions of educational priorities for community health professionals (as identified in the nominal group process)

3.1 Treatment and follow-up care, including pain and symptom management

Educational needs with respect to cancer treatment in the community were identified in the following areas: clinical practice guidelines and/or protocols, chemotherapy, pain and symptom management, radiation therapy, and knowledge of tertiary centre resources.

Educational needs pertaining to pediatric treatment were discussed in two groups, and needs related to chemotherapy and supporting children and families through the process were identified. Some participants raised that not all centres had the necessary teams in place to deal with pediatric cancer. (please refer to Appendix H section 5.2.2 for specific pediatric needs) (see footnote [5])

In each group, clinical practice guidelines, or in the case of the IWK, COG standards and protocols, were clearly identified as the foundation for treatment and were an important educational need.

> "But [another participant] is right, there needs to be more education around clinical practice guidelines for all disciplines and particularly, in cancer care best practices [...]. We said they needed to be shared more, there's not a lot of people [who] understand what clinical practice guidelines are, and what ones are out there governing practice..."

3.2 Knowledge of tertiary centre resources

Across groups, an increased awareness and understanding of tertiary centre resources was an identified educational need for professionals working outside the centre, particularly physicians and nurses.

In pediatric cancer care, the use of the IWK as a referral centre was emphasized for 1) diagnosis with its specialized expertise and ancillary studies (important since diagnosis is the foundation for treatment), 2) treatment as part of the Children's Oncology Network, and 3) as a "back up" resource.

Participants communicated an awareness that professionals in the community did not always know what happens at the centre (e.g. radiation therapy), and they expressed considerable interest in helping them become more familiar with the centre. Ways suggested to increase awareness included: practicums or specific educational experiences (e.g. chemotherapy), open houses, virtual tours, videos, and pamphlets. Some participants indicated some resources were presently under development.

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[5] The complete Tertiary Care Detailed Report (Appendix H) is available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

3.3 Awareness of community resources

One group identified improved knowledge about other supportive resources, such as those offered by the Canadian Cancer Society, especially the toll-free contact number, as an educational need. Community-based providers could help their patients access resources earlier in treatment, receive information, and experience less anxiety.

3.4 Other learning needs

Other educational needs included palliative and spiritual care; however these needs were not discussed in depth.

3.5 Cancer Centre staff's perceptions of educational priorities for community health professionals (as identified in the nominal group technique)

The nominal group prioritizing exercise reinforced the educational needs identified through the focus group discussion process. The educational priorities for health care professionals working in the community, according to cancer care staff at the three tertiary centres, are listed below (refer to Appendix F for the complete nominal group results by centre):

QEII Cancer Care Centre

(1) The majority of participants indicated that community health professionals need to increase their knowledge about *understanding others' roles in the cancer process and patient navigation*. Patients need to know who is directing their care and who they should call when they have questions or problems.

(2) An *increased awareness of available resources* was also identified as a priority. Cancer centre staff felt that community health care professionals need a better awareness of the resources and services available to patients in their own community.

Cape Breton Cancer Centre (same as for cancer care staff)

(1) *Psycho-social needs* were identified as the educational priority for community health professionals. Specific topics included: recognizing and providing for spiritual needs, giving bad news to patients, and supporting patients after they receive bad news.

(2) *Treatment & follow-up* – focus group participants indicated that more education for community health professionals is needed in the administration and side effects of chemotherapy, and in pain management.

IWK Cancer Centre

(1) Awareness of *facilities and resources* available at the IWK, as well as the roles of the various cancer care staff. Community health professionals need to know when to ask questions and who to ask at the IWK.

(2) Formal education about the *communication system between the IWK and Community*, and how pediatric oncology differs from adult oncology.

(3) *Treatment & follow-up*. Specific topics identified were: learn what to expect following treatment; anticipate treatment outcomes; how to assess and identify oncological emergencies, and know when to refer back to IWK.

4. Meeting Educational Needs

Groups variably explored meeting educational needs. Limited information was obtained on interdisciplinary education. Participants identified some means to reach out to the community, including strategies to increase awareness of the centre's resources, Telehealth and 'traveling teams' or 'road shows'.

4.1 Reaching community professionals

Ways to reach out to the community professionals included 'traveling teams' or 'road shows' and Telehealth.

'Traveling teams' or 'traveling road shows' were discussed in all three groups as a means to provide education in the communities, though there are resource considerations in terms of staffing and financing such an initiative.

Telehealth was raised as a means to provide education and to facilitate transfer of patient care to the community. However, some limitations were cited and included: frustrating, poor quality reception and inconvenient times and locations. As well, it was suggested that Telehealth does not meet the learner's need to network with the educator in the same way as face to face conferencing. Similarly, the IWK group noted with cutbacks, there is now less travel to the patients' home community, and some interest was expressed in evaluating direct contact and Telehealth transfer.

4.2 Networking

Networking to keep current was prominent in two groups and across disciplines. The IWK group emphasized networking with other COG members. There was also some interest expressed in the IWK group in exchanging experiences and approaches with adult cancer treatment providers. The Cape Breton group advocated sharing among other treatment centres, especially with respect to practice guidelines. This group suggested a regular continuing education opportunity with their Halifax counterparts (such as a symposium), possibly rotating the location.

The following comments illustrate concerns that reduced education budgets will reduce opportunities to network, which serves as an important means to update knowledge about treatment and resources.

> "…when budgets are being cut, they seem to cut the ability to be able to network, and it's essential that individuals are able to network, and that networking provides often time essential contact for work that's being done in the hospital as well as up date individuals on a day to day basis…" (physician)
>
> "…sometimes local conferences and networking -- you start to see channels that you never knew existed, and that is […] the benefit. And that is one of the things that does get cut is conferences and the education, but that's the part that opens up those networks and makes you increase your awareness." (nurse)

4.3 Interdisciplinary education

Interdisciplinary education was not addressed directly by the groups, but some discussions contained interdisciplinary content. The limited data suggested there were both positive and negative experiences with interdisciplinary education. Sharing conferences and other educational opportunities was discussed in very positive terms across disciplines in one group. e.g. "It's also a good thing for us a team." Attending oncology grand rounds helped meet the information needs of some nurse participants, who indicated other disciplines could also benefit, particularly if the presentation was adjusted to make content more easily understood. Discussion also indicated attitudinal barriers are sometimes encountered with respect to including non physicians in physician oriented events.

4.4 Barriers to CE

A prominent theme across all groups was the *resource constraints* that participants and the community experience first hand, and affect continuing education by posing barriers to educational opportunities and involvement. Several examples of the interrelated time and human resource barriers were described by participants. One participant pointed out,

> "But without the time, and in order to have the time you need personnel, in order to have personnel, you need the money. So they all link together. If you have the money, personnel, time then a lot of the other educational issues, the follow up, the community care, the models we are talking about then fit into place."

DISCUSSION AND LIMITATIONS

The community focus group findings, based on multidisciplinary perspectives, highlight the interrelationships between continuing education, cancer care delivery, and systemic contextual factors. These factors include resource limitations, geographical barriers, and cancer care system communication and coordination problems. These interrelationships suggest for these participants, that updated cancer knowledge will be acquired and used more easily and effectively, if systemic issues are addressed simultaneously. Knowledge related to treatment and resources for patients may have a synergistic potential to facilitate "seamless" patient care if system wide communication and coordination is improved. Interdisciplinary education may also play a role in this respect, particularly for appropriate topics or areas that are conducive to multidisciplinary approaches. The significant resource barriers that constrain the delivery of health care in the districts will need to be considered in planning new models of cancer care delivery and continuing education initiatives.

The tertiary centre focus groups provided information to enrich an understanding of participants' perceptions of tertiary centre role, their own cancer educational needs and those of health care providers in the community. For these participants, the central role appeared to be providing, directing/guiding and ensuring up to date cancer treatment. Associated with that role are important resource and educational roles. Linking the patient with the community is another aspect of the overall tertiary centre role.

Knowledge of up to date treatment is a perceived need for both tertiary centre and community providers. Aspects of team work, such as understanding roles and responsibilities and effective communication is an educational issue associated with delivering cancer care closer to patients' homes. This was particularly apparent in one group articulating a model of shared, interdisciplinary care. For community providers, knowledge of tertiary centre resources is another educational focus. A willingness to reach out to communities was evident among participants, though resource constraints were noted. As reported in the community focus groups, health care professionals in the tertiary care centres also indicated that significant interrelated time, human resource and funding resource barriers affect educational involvement and opportunities.

Some inherent limitations in these results need to be considered prior to developing and implementing recommendations. First, qualitative findings are specific to the participants and groups involved and are not generalizable in the quantitative research sense. Second, the nominal group process tends to limit discussion and hence, the data available for qualitative analysis.

And finally, the range and depth of the data obtained was probably affected by the heterogeneity within and between groups. Homogeneity is usually recommended for focus groups to facilitate comfortable discussion among compatible participants, with heterogeneity appropriate in instances where interaction between groups is an area of interest.[1] In this case, the interest in district cancer care models and interdisciplinary education appears to support the use of heterogeneous, interdisciplinary groups. The respectful sharing of information and friendly banter among participants suggest that participants were comfortable enough with each other to engage in the discussions. Nonetheless, it is still possible some participants, in the presence of others possessing different power and authority within their working relationships, may not have felt comfortable to freely comment on continuing education needs or system barriers they may perceive either within or outside their own discipline. As a result, findings may not completely portray all themes or significant factors related to a specific topic.

The impact of these limitations is lessened because the focus groups were only one data collection tool in the needs assessment process. The entire needs assessment was a comprehensive study including: questionnaires completed by family physicians, community specialists, nurses, pharmacists and radiation therapists; interviews with oncologists, and interdisciplinary focus groups in each district health authority and tertiary care centre. Results of each component of the study have been found to be generally consistent, and the use of different methods adds to the strength of the study. Consequently, these findings together offer a comprehensive view of health professionals' perceived education needs in cancer care.

OVERALL CONCLUSIONS

Findings of the 10 community focus groups and three tertiary care centre focus groups supported similar themes. Conclusions included the following:

Educational needs of community health professionals
Prominent learning needs, as identified by community professionals themselves and supported by perceptions of the tertiary care health professionals, included:

1. *Treatment and follow-up care, including pain and symptom management.* This need was strongly and extensively expressed across all groups and disciplines. Community health professionals need knowledge of their patients' (both adults and children) treatments and anticipated side effects, practice guidelines for continuing care, and, particularly, knowledge of appropriate pain and symptom management measures. Specific educational needs identified were:

   a. *Treatment*
   - The latest and most effective treatments; i.e., "We need someone to tell us…"this is what's current, this is what we know, this is what you can do""
   - Knowledge of and access to treatment guidelines, treatment protocols and standards of care;
   - Chemotherapy and treatment of its side effects, including appropriate medications; and
   - Lines & pumps – caring for portacaths, PICC lines, Hickman lines and CADD pumps.

   b. *Pain and symptom management, encompassing cancer symptoms, management of side effects and palliative care; e.g.:*
   - Pain management in treatment, follow-up and palliative care;
   - Changing physicians' ordering practices and improving nursing approaches;
   - Increased knowledge of pain and other medications (e.g., anti-emetics and "magic mouthwashes"); and
   - Nutrition information, especially to assist in counselling patients with disease symptoms or treatment side effects.

   c. *Complimentary & alternative therapies* - knowledge about the different types of therapies, their pros and cons, and nutritional aspects.

2. *Available resources and supports and how to access them for patient care.* Every focus group highlighted knowledge gaps concerning resources for patients. These included both resources available at the tertiary care centre and in the patient's community, and provincial and national resources, such as the toll-free Canadian Cancer Society information line.

3. *Teamwork: Roles and responsibilities of other members of the team* This includes knowledge of other team members' expertise and how they can contribute to cancer patient care, both within communities and tertiary care centres. This need was expressed across all disciplines.

4. *Patients' navigating the system.* This is an understanding by health professionals of the cancer care system and how patients have to navigate it, so that community health professionals can provide them with appropriate information and support. Especially important is an understanding of patients' treatment 'road map' and their experience at the cancer centre.

5. *Psychosocial care and patient communication.* All groups discussed aspects of psycho-social care and identified learning needs related to understanding the patients' needs and emotional responses, and being able to communicate appropriately and provide emotional support.

Educational needs of tertiary care health professionals
Prominent learning needs, as identified by tertiary care health professionals themselves included:

1. *Cancer treatment.* The most prominent educational need, based on the discussion data of the three groups, was keeping current with up-to-date information about cancer treatment, and maintaining clinical expertise. For the pediatric centre, maintaining membership with the Children's Oncology Network (COG) was critical in this regard.

2. *Teamwork: Roles and responsibilities of other members of the team.* A better understanding of teamwork was an important educational issue expressed among the groups. This includes understanding other team members' disciplinary roles and responsibilities, and how to effectively communicate with them. This knowledge was perceived to be important for facilitating patient care in terms of knowing "who the resources are" within some participants' own institution and/or in the community.

3. *Awareness of community resources.* Knowledge of community resources to facilitate patient and/or family access to supports when they return home (e.g. financial and psychosocial) was another tertiary centre educational need, expressed in two groups.

Role of tertiary care centres

All three groups indicated that the tertiary centres play three main roles: providing, directing/guiding and ensuring up to date treatment; being a resource, and providing education. Another role, related to the centre's overall treatment role was linking patients with their home community or other parts of the treatment spectrum.

Meeting educational needs in the community

Methods and strategies for meeting the educational needs of the community were discussed by the community health professionals. Tertiary care health professionals commented on their role in meeting these needs. The suggested methods included:

1. *Short, local sessions.* All groups and disciplines expressed a strong preference for short sessions, delivered locally and/or regionally and planned with sensitivity to local conditions. Some participants also indicated that local expertise and resources should be used more frequently.

2. *Case study approaches* received significant attention and positive appraisal from some groups and disciplines. Case study methods are beneficial due to their adaptability to many delivery mechanisms and formats, including print resources, inservices, study groups, the Internet, Telehealth, and workshops. Also, they are ideal for interdisciplinary sessions.

3. There was no clear preference regarding distance *continuing education delivery mechanisms. Telehealth* and the *Internet* received mixed reviews. Telehealth, while improving access was perceived to have at least two limitations: videotaping restrictions and a reduced amount of interaction. Some participants viewed the Internet as a means to more easily access protocols and guidelines.

4. *Interdisciplinary continuing education* appeared to be endorsed in principle by some participants, but its acceptability would depend to some extent on the topic. Palliative care emerged most clearly as a suitable topic for interdisciplinary education.

5. The tertiary care health professionals expressed an overall willingness to serve as a *treatment resource and provide education* for health care providers in the communities. Participants identified some strategies for reaching out to the community, these included Telehealth and 'traveling teams' or 'road shows'.

Systemic issues and barriers in continuing education and cancer care

All groups and disciplines indicated that significant issues and barriers impede their ability to provide optimum care and participate in continuing education programs. These include:

1. *Communication between the communities and cancer treatment centres.* Communication issues were identified in all but one community focus group. Poor flow of information from the cancer centre

regarding the patient's condition and treatment, including untimely reports was noted by a number of participants. Delays, duplication or missed follow-up were described as impacts. Sometimes community physicians and other health professionals have to rely on the patient for information. Also, the need for clearer guidelines was expressed, regarding who checks what, when and how.

2. The inter-related systemic issues of *funding, human resource and time limitations* (i.e., lack of coverage, loss of income for physicians and lack of paid educational leave for salaried health care workers) were identified as barriers to both patient care and continuing education.

3. The *financial burden of cancer care to patients* was of concern in several groups. Inadequate financial coverage for medications was emphasized.

4. To reduce the barriers that impede patients' access to care, some suggested providing chemotherapy and follow-up services closer to home.

RECOMMENDATIONS

Conclusions derived from the interdisciplinary focus groups reflect those resulting from the profession-specific needs assessment surveys reported earlier, for family physicians and community specialists, nurses and pharmacists (see footnote [6]). Hence, recommendations support those arising from these earlier studies, and readers are referred to those reports for complementary and additional data and results. Recommendations are presented under two headings:

1. Educational needs and preferred ways of learning
2. Systemic issues influencing cancer care

Educational needs and preferred ways of learning

Focus group discussions reinforced many of the educational needs identified in the earlier needs assessment studies, and recommendations are consistent with those. It is recommended that their implementation be guided by the *CCNS* Education Advisory Group.

1. For community health professionals begin to develop and implement programs that address the priority learning needs identified in the conclusions (refer to conclusion #1 for the community health professionals). These included treatment and follow-up care including pain and symptom management and complementary and alternative therapies, patients' navigation of the system, available resources and supports, teamwork, psycho-social care and patient communication.

2. Begin to respond to the more specialized learning needs of tertiary care health professionals:
   - Cancer treatment: Keeping current as tertiary care providers
   - Teamwork: Roles and responsibilities of and effective communication with other members of the health care team.
   - Community resources: Knowing what's available for patients when they return home

3. Implement educational programs and supports using the preferred methods:
   - Use short, local programs
   - Use case studies as they can be adapted to many teaching formats; e.g., face-to-face sessions, videoconferencing, Internet, self-study.
   - Further explore using telehealth/ videoconferencing and the Internet for educational programs.
   - Explore using interdisciplinary approaches to education for appropriate topics; e.g., palliative care, communication, pain and symptom management.

Systemic issues influencing cancer care.

Although systemic issues were not the focus of the discussions, each group addressed them and identified them as priorities for improving both cancer care and cancer care education. (Several are also identified as learning needs in the preceding section, "Educational needs".)

1. Respond to gaps and inefficiencies in communication and information-sharing among members of the health care team, with particular emphasis upon increasing communication between tertiary care centres and community health professionals. (It is recognized that the three tertiary care centres differ with respect to the extent of this problem, and readers are referred to the full text of the two focus group reports for more detail.) (see footnote [7])
   a. Establish an interdisciplinary collaborative working group representative of tertiary care health professionals (oncologists, nurse, pharmacists, etc), community health professional (family physicians, community specialists, nurses, pharmacists, etc) and patients to:
      - Explore gaps in communication addressed in the *CCNS* needs assessment studies, clarify issue and perspectives, recommend strategies, coordinate and oversee their implementation, and monitor and evaluate progress using a quality improvement model.

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[6] The complete Physicians, Nurses, and Pharmacists Needs Assessment reports are available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

[7] The complete Community Detailed Report (Appendix G) and the Tertiary Care Detailed Report (Appendix H) are available upon request from *CCNS*. Please contact Anne Murray at (902)473-3781 or email at anne.murray@ccns.nshealth.ca.

  - Explore specific options for enhancing communication among tertiary care and community health professionals, such as ensuring that community physicians are represented on *CCNS* site teams, using "checklists' or other simple communication tools when patients return to the community.
  - As part of this work, identify, clarify and educate all members of the cancer care team about the respective roles and skills of team members.

b. Respond to patients' difficulties in navigating the cancer care system and to the lack of health professionals' knowledge about their patient's cancer care journey. The latter prevents them from supporting patients adequately during their cancer care.
  - Explore options related to developing a patient "roadmap" or "journey map" which would identify the steps involved in each individual patient's "journey" and the health care professionals involved and their roles. This model could be tested and evaluated in one district.

c. Designate one staff person, knowledgeable about the health care system and cancer care, to guide the processes identified above related to communication among the health care team. This is a large task, and may require hiring or contracting an additional staff person.

2. Increase awareness of and access to resources for both tertiary care and community cancer care health professionals and their patients. This also includes resources available both through the community and in tertiary care centres.

3. Address, as possible, systemic barriers to continuing education – insufficient staffing, insufficient time, and lack of financial support for education.

REFERENCES

1. QSR NUD*IST 4 for Macintoshes. Qualitative Solutions & Research Pty. Ltd., 1997. (http://www.qsr.com.au)

2. Strauss A, Corbin J. *Basics of qualitative research.* 2nd Ed. Thousand Oaks, CA: SAGE Publications, 1998.

3. Patton MQ. Qualitative analysis and interpretation. In: *Qualitative evaluation and research methods.* 2nd ed. Newbury Park, CA: SAGE Publications, 1990:371-459

4. Miles MB, Huberman AM. Early steps in analysis. In: *Qualitative data analysis: an expanded sourcebook.* 2nd Ed. Thousand Oaks, CA: SAGE Publications, 1994:50-89.

5. Kruger RA. *Analyzing & Reporting Focus Group Results.* Focus Group Kit vol. 6. Thousand Oaks, CA: SAGE Publications, 1998.

6. Patton MQ. Enhancing the quality and credibility of qualitative analysis. In: *Qualitative evaluation and research methods.* 2nd ed. Newbury Park, CA: SAGE Publications, 1990:460-506.

7. Guba EG, Lincoln YS. Judging the quality of fourth generation evaluation. In: *Fourth generation evaluation.* Newbury Park, CA: SAGE Publications, 1989:228-251.

APPENDIX A: Community Focus Group Questions

1. **What are the educational needs and priorities for health care professionals in this district (knowledge, skills, attitudes)?**

Prompts:

- Do you see particular education needs for health professionals in:
    - Communication
    - Screening (i.e., breast and cervical cancer; digital rectal examination)
    - Appropriateness of work up tests before referral
    - Diagnosis
    - Pain management
    - Side effects
    - Medication
    - Palliative care

2. **Interdisciplinary education**

- Do you have experience with interdisciplinary learning?
- What are your attitudes/thoughts about interdisciplinary education for cancer care?
- What are the characteristics/criteria required for interdisciplinary learning to work? (e.g., opportunity to discuss common problems)
- What types of knowledge or skills would be appropriate for interdisciplinary education? (i.e. pain management, supportive/palliative care, cancer prevention education)

3. **Learning preferences**

- What learning methods would be best to meet your educational needs? (i.e. skills workshops, 2 day symposium, telehealth, Internet) *Try to be creative*
- Where would you prefer to attend education programs? (in your health district or in a central location?)
- What types of education issues and barriers does your health district encounter (i.e., geographic barriers, rural issues, demographics)?
- What community and educational resources are available to health care professionals in this district?
- Are there specific resources you feel you should have in your community for cancer care, but don't currently have?

4. **District Cancer Program**

- Have you heard of the District Cancer Program?
- Could this help resolve the barriers you identified?
- What do you see as your role in this model?
- Would a part-time Medical Coordinator with specialized education in cancer care be of assistance in your district?
- What do you think this person's roles should be? (chemotherapy, advice concerning side effects, liaison with hospitals)
- Would another administrator/coordinator position also be helpful?

5. **Final comments**

- Anything that we've missed?
- Anything you would like to add?

APPENDIX B: Tertiary Care Focus Group Questions

1. What do you see as the role of the tertiary care cancer centres in relation to the District Health Authorities (DHA) – regional hospitals, community based care - in providing cancer care to Nova Scotians?

2. Based upon your perspective as a health care professional in the cancer care centre, what are the needs or gaps in care that you see that might be addressed by education (knowledge, skills, attitudes)?
    - Please identify 3 educational needs specific to you and health care professionals in the cancer centre.
    - Please identify 3 educational needs specific to those who provide cancer care in the DHAs (based upon the patients referred to your center and the assistance requested of you by community health professionals)

    (record this info on the worksheet, indicate all the professions for whom this is a need).

    Prompts (only use if participants haven't mentioned these topics):

- Do you see particular education needs for health professionals in:
    - Communication
    - Screening (i.e., breast and cervical cancer; digital rectal examination)
    - Appropriateness of work up tests before referral
    - Diagnosis
    - Chemotherapy (Medication? Is this chemotherapy?)
    - Pain management
    - Side effects
    - Palliative care

3. Educational needs of health professionals at the cancer centre (record on flip chart).
    - What are your top 3 educational needs?
    - What types of education issues and barriers do you face at this centre?
    - Are there specific educational resources you feel you should have available to you, but don't currently have?

4. Educational needs of community health professionals (record on flip chart).
    - What do you perceive as the top 3 educational priorities for health care professionals who provide cancer care in the community?
    - What do you see as the role of health care professionals at the cancer centre in meeting the educational needs of the communities?
    - What resources and supports do you need to do this?
    - In what other ways could these educational needs be met?

5. Interdisciplinary education
    - What has been your experience with interdisciplinary learning?
    - What are your impressions about the value or usefulness of interdisciplinary education for cancer care?
    - What types of knowledge or skills would be appropriate for interdisciplinary education? (e.g. pain management, supportive/palliative care, cancer prevention education)
    - What are the characteristics/criteria required for interdisciplinary learning to work? (e.g., opportunity to discuss common problems)
6. Final comments
    - Anything we've missed?
    - Anything you would like to add?

APPENDIX C: Demographic Questionnaire

1. Occupation: ☐ Physician (indicate specialty if applicable) ____________________
☐ Nurse (please indicate specialty) ____________________
☐ Pharmacist (please indicate specialty) ____________________
☐ Other (please specify) ____________________

2. Do you have specialized education/training in oncology or palliative care?
☐ Yes, please specify ____________________
☐ No

3. Gender
☐ Male
☐ Female

4. How many years have you been practicing? ____________________

5. In what type of setting do you work? Please mark all that apply.
☐ Private office
☐ Regional or district hospital
☐ Tertiary care hospital
☐ Small community hospital
☐ Clinic
☐ Home care program/agency
☐ Nursing home/long term care
☐ Community health agency/centre
☐ Public health
☐ Other, please specify ____________________

6. In what health district do you primarily practice? ____________________

7. Over the last **3 months** how many patients have you seen with cancer?
☐ 0
☐ 1-5
☐ 6-10
☐ > 10

Thank you.

APPENDIX D: Nominal Group Worksheet

WHAT ARE THE EDUCATIONAL NEEDS AND PRIORITIES FOR HEALTH CARE PROFESSIONALS IN THIS DISTRICT?

Please list a minimum of 3 suggestions (for yourself and/or for others) and indicate the health care provider(s) for whom this is an educational need, on the table below.

	Health Care Provider						
EDUCATIONAL NEED(S)	**Family Physician**	**Specialist Physician**	**Nurse (indicate specialty)**	**Pharmacist**	**Social Worker**	**Dietitian**	**Other (please specify)**
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							
9.							
10.							

APPENDIX E: Community Nominal Group Results by District

Table 1: Southwest Nova District Health Authority (District 2)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Resources available – regular updates about who does what, what services available & what do they provide (e.g., CCS, HCNS, VON, PN)	9	Nurse (4) Pharmacist (2) Social worker (2) Physician (1)
More sharing of information among health professionals	5	Physician (2) Nurse (2) Social worker (1)
Treatment of nausea and vomiting	4	Pharmacist (2) Nurse (1) Dietitian (1)
Best practices re: nutrition, support, N & V, appetite changes, weight loss, change related to treatment modalities.	4	Dietitian (2) Nurse (2)
Pain management	4	Nurse (3) Pharmacist (1)
Grief counselling – staff/family	4	Nurse (2) Physician (2)
Telephone directory – cancer site teams	4	Nurse (2) Physician (1) Social worker (1)
How to advocate for healthy public policy. Government departments to work intersectarily	4	Dietitian (3) Social Worker (1)
Realistic & accurate expectations re: outcomes, prognosis	3	Physician (2) Pharmacist (1)
Best practices for common cancers	3	Physician (2) Dietitian (1)
Treatment options, cost of treatment	2	Nurse (2)
How to work effectively as a team to provide the best patient care	2	Pharmacist (1) Dietitian (1)
How to present bad news and how to deal with outcomes of giving bad news	2	Physicians (2)
Partnerships using population health model to promote healthy lifestyles	2	Dietitian (2)
Funding for drug assistance	2	Pharmacist (2)
Support groups	2	Nurse (2)
How to implement smoking cessation programs in the community	1	Pharmacist (1)
Options for psychological support, what is available: Internet, directions, links. Directory of services – locally, provincially	1	Physician (1)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP **(Southwest Nova continued)**	**PRIORITY RATING (# stickers)**	**PROFESSION(S)**
What damage is done by screening	1	Physician (1)
Education for men/women re: the screening process – risks & benefits – breast, PSA, colon cancer	1	Physician (1)
Screening recommendations. What are the real benefits – how many screened to prevent 1 death. What are costs? (cost/benefit)	1	Physician (1)
How to help patients know the roadmap for navigating the system	1	Physicians (1)
Dealing with self blame – why I develop cancer	0	
Countering false hope without being accused of being a "doom sayer"	0	
Which cancers respond well to treatment? Which do not?	0	
Prognosis for different type of cancer	0	
Support group staff/family/clients	0	
Post treatment follow-up	0	
Expectations for patients post treatment	0	
Health professionals involved with patient cancer care – who are they?	0	
Assessment of evidence	0	

Table 2: Annapolis Valley Health (District 3)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Pain management - Multidisciplinary education - How to administer - Effects on families & HP - Other ways to manage pain other than narcotics - when to take (patients) - how to take - relationship/coordination re: pain medication and other treatments/tests - pain medication givers (family, HP) need education - allergies to pain medications - assessment of pain for everyone, esp. non-verbal people	8	Physician (2) Nurse (2) Pharmacist (2) Dietitian (1) Spiritual (1)
Continuing updates for nurses re: treatment. Current standards, guidelines. New research protocols	8	Nurse (3) Physician (2) Pharmacist (2) Dietitian (1)
Complementary, alternative therapy - nutritional treatment of cancer – validity - all types	8	Physician (2) Nurse (2) Dietitian (2) Pharmacist (2)
Need education for patients, family, public (ie., risks, prevention, early Dx)	7	Nurse (3) Dietitian (2) Physician (1) Spiritual (1)
Availability of human resources to make multi-disciplinary care possible	5	Physician (2) Nurse (2) Spiritual (1)
How to best access chemotherapy protocols – latest, up to date, effective. Access to research protocols	4	Physician (3) Pharmacist (1)
What community & church supports are available for patients and families. How to access these supports/ support groups	4	Nurse (2) Physician (1) Spiritual (1)
Opportunity for education is limited by time, resources, money	4	Nurse (2) Physician (1) Dietitian (1)
Education in schools re: prevention	3	Physician (1) Nurse (1) Dietitian (1)
Preparations for tests and procedures – patient, HP - CT scans-contrasts – patient needs to know prior to test - Ultra sounds - Nuclear medicine	3	Spiritual (2) Nurse (1)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP (Annapolis Valley continued)	**PRIORITY RATING (# stickers)**	**PROFESSION(S)**
How to interpret studies/literature, e.g. what patient gets from Internet. How to explain appraisal to patient	3	Physician (1) Pharmacist (1) Spiritual (1)
Dealing with cancer patients & family in retail pharmacies – grief, helping patients cope	2	Pharmacist (1) Spiritual (1)
How to make prevention fun. Integrate prevention into our daily lives	2	Dietitian (2)
Support groups for patients and families needed	2	Spiritual (2)
Awareness of community resources	2	Nurse (1) Physician (1)
Community education for staff in Cancer Centres - Trainees (ie., residents) in Cancer Centres need to go to DHAs to see how things are done. Patients often told by trainees that they need care at Cancer Centre. Causes hardship within family – travel, support - Trainees need to see how cancer patients live their lives.	2	Physician (2)
Family physicians many not be able to keep track of all resources – educational & community. Need coordinator to call to meet with patient	1	Physician (1)
Education for staff in Dx Imaging re: cancer in general	1	Nurse (1)
Side effects of therapy/treatment	1	Pharmacist (1)
Safety re: handling of chemotherapy drugs – health professionals & patients	0	
Review cancer basics – types, treatment	0	
Environmental risks	0	
Coordination of support services on a volunteer basis	0	
Clinical trials – awareness, communication re: trials	0	
PDQ website – link on doctorsns.com	0	
Relationship/communication/consistency between local hospital/hcp and those in Halifax	0	
Videos may help, CD Rom, series videos re: main Ca sites – designed for/by Nova Scotians (*CCNS*)	0	
More than 3000 patients with no physician in this district	0	

Table 3: Cumberland Health Authority (District 5)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Oncology therapeutics – pharmacists and other HCPs need more education re: meds, doses, side effects, new meds, radiation, etc	6	Nurse (4) Pharmacist (1) Physician (1)
Communication between oncologist, family physician & nurse going into patients home. Need written communication from physician re: medications, Dx, prognosis lab results	5	Nurse (3) Physician (1) Diagnostic Imaging (1)
Continuity of services for whole province. Equal distribution of money, avoid duplication of services, eg. Patient Navigation	5	Nurse (5)
Pain and symptom management post chemotherapy/radiation – may differ from symptom management for P/C patients	4	Nurse (3) Pharmacist (1)
Change standards in long term care to provide more palliative care, eg. pain pumps, VON coming in to provide these services. Utilizing P/C team.	4	Nurse (4)
Standards of care re: chemo between NB & NS. Orders from Moncton are multicopied. Can't read. May result in errors. (Home Care nurse should be part of cancer care team)	4	Nurse (4)
Care of the dying child	3	Physician (1) Nurse (1) Coordinator palliative care
Advocating for patient, especially elderly & very young. Being truthful. Honest about death. Family involved.	3	Nurse (2) Coordinator palliative care
Availability of services available in district – patient, families, HCP need to be aware	2	Coordinator palliative care Diagnostic imaging (1)
Better contact with NS Breast Screening Program. Amherst does diagnostic mammography. Screening done through family physician	2	Physician (1) Diagnostic imaging (1)
Dealing in community with patient's response to cancer treatment. Constantly reacting, no proactive stance	2	Nurse (1) Pharmacist (1)
More comfortable with patients preparing to die. Help patients be comfortable. Allowing it to happen. Being supportive.	2	Physician (1) Nurse (1)
Better use of teleconferencing facilities between Moncton oncologists and Cumberland Health	2	Nurse (2)
Underutilizing services of volunteers – could go to appointments with patients, assist in chemo clinic, drive patients to appointments	1	Coordinator palliative care
Should there be Well Mens clinics?	1	Nurse (1)
Further education on Breast Screening Program and guidelines. Also cervical screening, colon cancer.	1	Diagnostic imaging (1)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP (Cumberland Health continued)	**PRIORITY RATING (# stickers)**	**PROFESSION(S)**
No liaison person in Moncton	1	Diagnostic imaging (1)
Diagnostics in elderly. Lost in long term care. What follow up is needed. Treating signs & symptoms not disease process	1	Nurse (1)
Alternative therapies – music, art, meditation, massage, therapeutic touch	1	Coordinator palliative care
Complementary therapies – herbal, shark fin, apricot seeds, pot	1	Pharmacist (1)
Integration of treatment & symptom relief into long term care	1	Nurse (1)
Drug costs – pain meds don't qualify for social services & fall through cracks. Sometimes patients admitted to receive their medications	1	Pharmacist (1)
Communicating bad news – how oncologists/specialists deliver bad news	0	
Nutritional education for cancer patients	0	
Well Women's Clinic in Pugwash, Parrsboro, Springhill (nurse practitioner), Advocate. None in Amherst. All female FP in Amherst will see women for screening procedures.	0	
In Dx Imaging staff are left out of the loop. No P/C training. Not taught about how to deal with the way patients are feeling.	0	
Developing support systems for family & staff in long term care	0	
Patients from IWK better prepared (ie. receive binder with info). Can this be translated to info for adults. Template exists	0	
Moncton physicians not aware of services in Cumberland Health District	0	
Participation in clinical trials may limit patients options	0	

Table 4: Pictou County Health Authority (District 6)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Improving knowledge of chemotherapy drugs and side effects.	7	2 physicians 4 nurses 1 pharmacist
Easy access to up-to-date concise treatment guidelines: internet site, 1-800 number. Follow-up guidelines: a) intermediate, b) long term.	7	2 physicians 4 nurses 1 pharmacist
Use of medications in pain and symptom management, legal & ethical issues.	6	2 physicians 3 nurses 1 pharmacist
Communications skills re giving Dx and dying. Working with patients & families.	6	4 nurses 1 coord. volunteer services 1 pharmacist
Guidance-based guidelines on prevention & screening – HP and public educations – expectations for realistic outcomes.	5	1 physician 4 nurses
Team approach: lack of communication from cancer centre → district → community.	5	4 nurses 1 coord. volunteer services
PICC lines, Hickman, CaddPumps, Infuser Pumps	3	1 physician 2 nurses
Understanding of each other's role and working interdependently.	3	1 nurse 1 coord. volunteer services 1 pharmacist
Unmet needs of spiritual care.	3	2 nurses 1 coord. volunteer services
Pathway re how to deal with febrile neutropenia.	2	1 physician 1 nurse
Lack of knowledge about community & hospital-based resources, assistance available, how to access.	2	1 nurse 1 coord. volunteer services
Evidence-based, up-to-date lists of environmental toxins.	1	1 physician
How to access referral system in Halifax.	0	
Pros & cons of alternative medicines.	0	
Preparation for visits to oncologists.	0	
How to provide seamless care.	0	

Table 5: Guysborough Antigonish Strait Health Authority (District 7)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Published set of standards of care. Internet based algorithms for pain medications. User-friendly manuals, care plans, procedures & techniques. Cancer Centre in Halifax needs awareness of what is available in district.	7	3 nurses 2 physicians 1 lab tech 1 pharmacist
Improved communication between hospital & community HPs (e.g. fax, email), e.g. teleconference.	5	2 nurses 1 lab tech 1 spiritual 1 pharmacist
List available in Cancer Centres of services available in the Health Districts – Patient Navigator could be liaison.	4	1 physician 1 nurse 1 pharmacist 1 lab tech
Email/fax list of all HPs wishing to receive Continuing Education communications.	4	1 lab tech 1 spiritual 1 pharmacist 1 physician
Ability to communicate medical terminology in lay terms. How to get the message across – verbal, written, videos, communicating stages of disease. Making informed choices. Self/family advocacy.	3	2 nurses 1 physician
Family physicians need understanding of where patient goes, what happens – physical process.	3	1 nurse 1 physician 1 lab tech
Community specialists other HP need to be part of team. QEII Cancer Program needs to support community specialists. DHA physicians need cspiritualibility from cancer centre staff.	2	1 physician 1 nurse
Lack of time, funding, resources for continuing education. Community specialist can't take time away from practice to CE events.	2	1 pharmacist 1 physician
Educational needs for Cancer Centres in Halifax: – Communication protocols, checklists – Geography awareness re length of travel time and best times for appointments – Checklist re follow-up care, required side effects and how they are dealt with	1	1 spiritual
Communication skills re caring for patients with cancer – providing emotional & spiritual support throughout the cancer journey.	1	1 spiritual
Ways to educate HP team – attend Oncology Nurses' Day at Cancer Centre.	1	1 nurse
Lack of awareness of resources available within the District – where chemo is available, Patient Navigator, District Cancer Program.	0	
List of educational references for HPs.	0	

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP **(Guysborough Antigonish Strait continued)**	PRIORITY RATING **(# stickers)**	PROFESSION(S)
Resources – how realistic are they to carry out recommendations (screening)?	0	
Videoconference of oncology rounds – don't know about.	0	
Signs & symptoms – healthy public. Increasing public awareness.	0	
Video equipment etc. that patient might see in Cancer Centre. Video of the Cancer Centre itself.	0	
End of life issues: – DNR orders etc. – Enabling patients to die at home/hospital according to their choice. – When to introduce P/C to patient & family.	0	
Systemic problems capturing treatment protocols from District Health Authorities.	0	
Participate on site teams.	0	

Table 6: Cape Breton District Health Authority (District 8)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Flow chart to indicate the patient's cancer journey to improve communication with health professionals – could discuss at continuing education for pharmacists, VON, palliative care team.	8	2 others 3 nurses 2 pharmacists 1 physician
Awareness of options available for treatment in NS & Canada.	6	2 pharmacists 2 physicians 2 nurses
Knowledge of what is available in the community, e.g. VON – how to contact. – Road map needed & Awareness of Cancer Information Services number.	6	2 pharmacists 1 physician 2 nurses 1 other
Management – therapies used. Treatment: chemo, radiation, side-effects of treatment.	5	3 nurses 1 pharmacist 1 physician
Community lay educators providing cancer prevention education. – What is it that women want to know? – Adult education and small group facilitation skills – Counselling skills & High school wellness clinics - making dates and places available to women. Education via lay educators.	5	2 nurses 2 pharmacists 1 other
Communication problems between members of health care team – immediate dissemination of new knowledge to health professionals – increased Canadian content on internet re clinical trials etc.	4	2 physicians 1 pharmacist 1 other
Public education re taking charge of their own health care, self-advocacy.	2	1 other 1 nurse
Forum for all care providers to meet and discuss patient/family needs. Barrier-free structure and time.	2	1 nurse 1 other
Needs for RNs providing pap smears in rural areas of districts 7 & 8, GASHA, CBHA (Periodic reviews – anatomy & physiology; Creative ways to access unscreened and underscreened populations).	1	1 other
Knowing that you are getting leading edge advice from specialists.	1	1 nurse
Use of nurse practitioners.	1	1 other
Delayed Dx due to availability of tests. Preferred diagnostic routes – effective, cost-effective.	0	
To increase role of family physician in providing supportive care. They need understanding of what cancer specialists are looking for, prognosis, treatment.	0	
Who is responsible to follow-up care? Who does what, when? Coordination.	0	
VON: Dealing with emotional issues, e.g. end of life care, grief, dying, anger, denial.	0	
Lobby with government and universities to increase numbers of health care professionals.	0	

Table 7: Capital Health (District 9a)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Information re: treatments, advancements and changes	3	1 pharmacist 1 nurse 1 social worker
Symptom & pain management, adverse affects of chemo & other meds. Pain clinic referral	3	2 nurses 1 physiotherapist
How does treatment & nutritional status affect activity/exercise levels?	2	1 nurse 1 physiotherapist
Guidelines for provision of care	2	1 social worker 1 pharmacist
Hands on experience at the Cancer Centres. Preceptorship	2	1 pharmacist 1 nurse
End of life care, living wills, dying at home	2	2 social workers
Understanding emotional needs of patients e.g., families expressing anger, coping mechanisms	2	1 nurse 1 physiotherapist
Meeting emotional needs, psycho-social needs	2	1 social worker 1 nurse
Cultural & ethnic practices re: health in general & cancer	2	1 nurse 1 social worker
Training health care professionals how to care for themselves	2	1 nurse 1 social worker
How to motivate, enable staff to take part in educational opportunities	2	2 nurses
Person first dealing with patient and giving Dx need more information re: community supports. How to access support services? What is available. Along continuum of care.	2	1 nurse 1 physiotherapist
Readily accessible Internet resources. What is leading edge? What works? How to find reliable sites? Warning patients re: misinformation	2	1 pharmacist 1 nurse
Need interdisciplinary education. Work as a team. Continuity of care.	2	1 pharmacist 1 physiotherapist
Ethical dilemmas – how to deal with? What are they?	2	1 nurse 1 social worker
Current evidence based prevention	1	1 pharmacist
Seven signs of cancer, when/how to recommend referral to physician. Pharmacists, hair dressers re: skin cancer	1	1 pharmacist
Work with CCS to develop list of patients to talk with others	1	1 nurse
Life long learning – how are we going to do it? Continued resource development & awareness/access	1	1 pharmacist
Hands on experience/info re: dietary aspects of care-treatment, support, prevention	1	1 nurse

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP **(Capital Health 9a continued)**	PRIORITY RATING **(# stickers)**	PROFESSION(S)
Cancer site specific information for patients. More detailed for staff	1	1 pharmacist
Seamless care: Home – FP – cancer centre – home	1	1 nurse
Improved communication skills	1	1 pharmacist
Working (facilitating) with groups, developing groups skills to bring people together to discuss needs as a group. Working with elderly patients	1	1 social worker
Better communication among all health care providers. Community & institution. Cancer centre charts not always accessible	1	1 nurse
Understanding patient confidentiality issues.	1	1 social worker
Patient has own chart- "passport"	1	1 nurse
Pal Com Course at highschool – impact on this re: cancer prevention/screening	1	1 nurse
Mentoring program re: starting Ivs, skills labs – Port-a-Cath, refresher courses	0	
Evidence based care across the cancer continuum	0	
Different ways to administer medications. Patches	0	
Bereavement care	0	
Address needs of different age groups	0	
Training from actual cancer survivors re: their perceptions of their journey & care. Also from family members	0	
Understanding why people change and how to motivate them. "Stages of change"	0	
Early cancer prevention at school	0	
Cancer prevention at Maternity hospitals for new parents	0	

Table 8: Capital Health (District 9b)

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	PROFESSION(S)
Communication skills with other health providers. Team approach to patient care.	5	2 physicians 1 dietitian 1 nurse 1 social worker
Alternative therapies in cancer care.	4	2 physicians 1 dietitian 1 nurse
Discussion of death, dying, and end of life care. Providing comfort.	3	2 nurses 1 social worker
Resources available in Capital Health: hard copy, electronically, Med Society, Dal refresher.	3	2 physicians 1 dietitian
Awareness and increased knowledge re psychosocial issues and appropriate interventions.	3	2 nurses 1 social worker
Pain and symptom management	2	2 nurses
Education re newest diagnostic methods/tests. Prevention and screening. Information re diagnostic imaging/tests that exist.	2	2 physicians
New treatments and current research, clinical trials.	2	1 physician 1 nurse
Lack of general awareness among HP of costs ($) of cancer treatment. Loss of work. Supportive care costs.	2	1 physician 1 social worker
How culture affects people's reaction to disease, treatment & follow-up care, death & dying.	2	1 dietitian 1 nurse
Information for patients and families re diagnosis and treatment.	1	1 nurse
Learning to educate people about how healthy choices can impact cancer prevention.	1	1 dietitian
Issues related to AIDS patients with cancer.	0	
Hospice model of care.	0	
Interactions between cancer treatment and treatments for other medical problems, especially if person is part of a clinical trial.	0	
Nutritional needs of patients with breast cancer.	0	
Meeting spiritual needs of patient. Bereavement needs of family.	0	
Forum case presentations outlet for health professionals working with cancer patients. Dealing with personal grief, anger re loss of patients.	0	
How we treat people differently in relation to age. Should we? Consensus & support to help physicians, HP, patients, families involved in these decisions. Education re Directive of Care.	0	
Care of the caregiver.	0	
Ethical issues – need way to address ethical issues surrounding patient care.	0	
Accountability and responsibility of administration, e.g. IT systems – making it compatible across province.	0	

APPENDIX F: Tertiary Care Nominal Group Results by Centre

Table 1: QEII Cancer Centre

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	NEEDS OF COMMUNITY HPs	NEEDS OF CANCER CARE STAFF
Basic oncology information, medical terms, implications of Dx and prognosis on psychosocial aspects of patient's life. Helps to know questions to ask patient.	8		2 nurses 1 OT 1 Physicist 1 radiation therapist 1 physician 1 social worker 1 chaplain
Patients to know who is directing their care – who to call, e.g. refills on meds. Patient navigation a good one.	7	2 nurses 2 radiation therapists 1 OT 1 Physicist 1 chaplain	
Aware of other resources & services available to patient in their own community and make links prior to coming to Cancer Centre.	6	1 OT 1 Physicist 2 radiation therapists 1 social worker 1 chaplain	
HP increase awareness of what happens in a cancer centre – tour of centre by HPs.	5	1 OT 1 Physicist 1 radiation therapist 1 social worker 1 nurse	
Understand process from Dx → Tx → PC. RNs float to Cancer Centre & P/C for six-month period. Opportunity to see what others do.	5		1 OT 1 Physicist 1 nurse 1 radiation therapist 1 chaplain
Pain & symptom management, esp. family physicians and nurses.	3	2 nurses	1 physician
Spend time in other areas of clinic – e.g. RT spend time working with RN & others.	2		1 social worker 1 radiation therapist
Oncologists and P/C physicians' maintenance of clinical expertise: "Work in a vacuum", "Learn who the resources are."	2		1 physician 1 OT
Need feedback about the patients who do well and who haven't. Gaps in continuum.	2		1 chaplain 1 social worker
Know about emotional & financial support programs available around province.	2		1 radiation therapist 1 nurse

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP (QEII Cancer Centre Continued)	PRIORITY RATING (# stickers)	NEEDS OF COMMUNITY HPs	NEEDS OF CANCER CARE STAFF
Expert knowledge of chemo - predictable and less common side effects – regional level.	1		1 physician
Provide information at Dx prior to appointment at Cancer Centre. CIS number.	1	1 nurse	
Recognition by care providers of family stress & overload, traveling social worker, respite care for family – necessary, positive.	1	1 radiation therapist	
Awareness of job stress & burn out.	1		1 physician
Know about follow-up plans for the patient in order to advise.	1		1 physician
Ability to connect with workshops.	1	1 social worker	
Role of spiritual care to help face cancer with their inner resources. Place health & healing in patient's hands. Core issues when dealing with cancer – help other HP to understand.	0		
Full understanding of process.	0		
Enhance role of family physician in terms of pain & symptom management. Have family physicians come to Cancer program & P/C to spend a few days.	0		
Understand lymphedema symptoms and treatment options.	0		
Aware of lymphedoma resources.	0		
Formal support groups that are site specific.	0		
Education re healthy lifestyles & cancer prevention.	0		
Network of trained cancer survivors – buddy – in community when patient leaves Cancer Centre.	0		
Survivors' wall – quilt.	0		
Non educational needs/issues			
Encouragement & time to attend (continuing education) oncology rounds, site specific rounds. RTs unable to attend due to work schedule.	6	1 chaplain	2 radiation therapists 2 nurses 1 physicist
Barrier: No budget for CE at QEII. – Incentives to attend – burnout may prevent staff from coming. – E.g. yard sales to raise $ to attend CE. – Don't see benefits – what benefits come from CE? – Time may be an issue. – RT – staffing (is done on own time).	0		

Table 2: Cape Breton Cancer Centre

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP	PRIORITY RATING (# stickers)	NEEDS OF COMMUNITY & CANCER CARE HPs
Recognizing & providing for spiritual needs.	8	1 nurse 2 nurses 1 dietitian 1 manager 1 social worker 1 physician 1 chaplain
Health promotion for general public – expanded role of tertiary facility, gyne screening program, youth health centres. Start elementary school work with public health. Role for District Cancer Committee. Need prevention coordinator – to not take staff from CBCC.	7	2 nurses 1 physician 1 social worker 1 chaplain 1 manager 1 dietitian
More education for family & emergency room physicians and health professionals – chemotherapy administration & side effects. They receive dictated notes from oncologist which are not always read. Use teleconference to communicate with physicians. Time & place of teleconference is an issue.	7	2 nurses 1 pharmacist 1 physician 1 nurse 1 manager 1 dietitian
Education based closer to home – traveling educators, students can travel outside of Halifax.	5	1 social worker 1 dietitian 1 manager 1 chaplain 1 nurse
How to give bad news to patients and supporting patients after receiving bad news.	3	1 chaplain 1 physician 1 nurse
Increase communication re educational resources available.	3	1 pharmacist 1 nurse 1 dietitian
Nutritional screening and assessment tools specific to oncology. Oncology network DC. Contact other centres.	2	1 nurse 1 dietitian
Pain management.	1	1 physician
Clinical practice guidelines – don't reinvent the wheel. Share.	1	1 nurse
Meditation, cognitive therapy techniques for cancer patients.	1	1 social worker
More involvement of hospital pharmacists in clinical care.	1	1 pharmacist
Increase education re radiation therapy. Side effects of why, how, how much for staff in entire CB District.	0	
Alternative and complementary therapies.	0	
Issues of patients needing palliative care vs. treatment.	0	
Family physicians feel patients are no longer theirs once they see oncologist. Lose "ownership".	0	

EDUCATIONAL NEEDS IDENTIFIED IN NOMINAL GROUP **(Cape Breton Cancer Centre Continued)**	PRIORITY RATING **(# stickers)**	NEEDS OF COMMUNITY HPs
Coordination with hospital and retail pharmacists re protocols, side effects, new therapies.	0	
Develop patient-focused teams.	0	
How to meet spiritual needs of staff who are dealing with cancer patients – futility of some treatments.	0	
Role of spiritual needs in providing end of life care.	0	
Use of internet as a learning tool – health professionals and patients.	0	
Resources not available to make use of education already available.	0	
Share educational opportunities with QEII/IWK program.	0	

IWK Cancer Centre: The participants in the IWK focus group identified a number of needs, and then spent time collapsing them into 2 overall categories: community needs and tertiary care needs.

Table 3: Community needs according to participants of IWK focus group.

1.0	Awareness of facilities at IWK and awareness of IWK of community resources. Aware of constraints on IWK resources.
1.1	New health professionals in community have visit and/or virtual tour of IWK. Need specific goals for visit.
1.2	Need to know when to ask questions & who to ask at IWK.
1.3	Tertiary care back up – able to contact specialists (all professions) at IWK when needed.
2.0	Formal education/communication system between IWK/Community. Ped. Oncology differs from adult oncology.
2.1	Learning what to expect following treatment – anticipating outcomes of treatment. How to assess & identify oncological emergencies. When to refer back to IWK.
3.0	How to support children in an adult centre & in community.
4.0	Just before /"Just in time " education for community health professionals.
4.1	Education at comm. level is very facility specific. Some small facilities may not see patients often enough or be prepared to care for some patients.
5.0	Understanding of COG in community.

Table 4: Tertiary care needs according to participants of IWK focus group.

#1 priority: Increased awareness and knowledge of reality of patient's home life, family and community, and the resources available in that community to assist them when they return.

1.1	Good understanding of: - psychosocial needs - family dynamics - team work - when to refer to other disciplines - effect of illness on family - stages of Dx, P/C and effect on family/siblings - how children cope with hospitalization
1.2	Exchange of treatment protocols, side effects between adult & pediatric communities for all disciplines.
1.3	Maintain awareness of psychosocial, physical, economical challenges that patients face in community.
1.4	Understanding necessity of undertaking & maintaining relationship with health professionals in community.
1.5	Ability of each discipline to do effective family assessments & recognizing needs of patient/family in their homes. Recognize when families, communities are struggling.
1.6	Increase knowledge of resources in community. Advocate for community resources
1.7	Telehealth can be used to transfer patient to community – meet with community team.
2.0	Keeping current – clinical care to cover spectrum of patient needs (Treatment, Dx, Psychosocial, supportive care, oncological emergencies, etc.).
2.1	Essential to have: expert, specialized training in ped. oncology.
2.2	Access to current, up to date information via research, experts, attend conferences
2.3	Ability to network and meet with other experts and other facilities.
2.4	Awareness of COG (Children's Oncology Group) (accreditation) in community but also awareness within own IWK administration – networking with other COG experts is essential. - need training for accreditation to be maintained.
3.0	Improving communication skills.
4.0	IWK have staff representative on each District Cancer Committee.
	Support systems for new health professional staff.

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Furthering Cancer Education in Nova Scotia:

Interdisciplinary Focus Groups

Appendix G
Community
Detailed Report

Appendix H
Tertiary Care
Detailed Report

February 2003

Cancer Care Nova Scotia

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Interdisciplinary Focus Groups

Appendix G

Community Detailed Report

February 2003

prepared by
Elaine Loney, M.Sc

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EXECUTIVE SUMMARY

Findings pertaining to educational priorities and cancer care issues are presented from 10 multidisciplinary focus groups, held in 9 Nova Scotia district health authorities from April-June 2002. Overall, 98 health care providers participated. Nurses (44), physicians (18) and pharmacists (14) comprised 78% of participants overall, with the 22% remaining participants from 8 other disciplines.

Qualitative analysis methods were used. Transcripts were verified, and imported into QSR NUD*IST for data management and systematically coded; that is, broken down into meaningful units and assigned to categories. Themes were identified and interpreted.

Summary of Key Findings

- Educational Needs, Preferences & Issues: Participants identified important learning needs related to treatment, including pain and symptom management, resources and other team members' roles. This participant's comments captures the prominent educational themes:

  > "I would I think, I as a physician, need to be educated by specialists who are doing that kind of work as to what the new treatments are, what's appropriate, when to do this and when to do that. But at the same time, I'm lost when it comes to knowing, you know, what's available in the community. What's available to people who have cancer, who you're working with and how you're going to either…so there's a whole big education there that we have to…I think, for physicians to understand we're part of a team and we need to know who's on the team" (physician)

  Participants, providing health care in a context of resource limitations, expressed a strong preference for local/regional delivery of short continuing education sessions. While there appeared to be some support for interdisciplinary education in principle, its acceptability may depend on the topic (e.g. palliative care).

- Systemic Issues: While the main purpose of the focus groups was to examine the continuing education needs and learning preferences among health care disciplines in the districts, themes also emerged pertaining to systemic issues in cancer care. Participants illuminated communication and coordination issues, particularly in working with the cancer treatment centre.

  > "…it becomes a specialist's world in terms of care of the oncologists for the patients and the family doctor is often left 'out of the loop' " (nurse)

  Participants identified the significant human resource, time and funding barriers that constrain their ability to participate in continuing education and affect the delivery of cancer care at the district level.

- District Cancer Care Model: Funding was a primary concern of the three groups discussing the District Cancer Care Model.

> "So to talk about district cancer care until the funding issue has been addressed…I think everyone's skeptical that it's going to fly." (physician)

Educational Needs, Preferences & Issues

Prominent Learning Needs

Treatment, Pain & Symptom Management Educational needs related to treatment, including pain & symptom management, were most prominent. They were strongly and extensively expressed among and across disciplines and groups. Some participants recognized a need for both themselves and their colleagues to update their knowledge concerning the current, most effective treatments. Participants described how knowledge of treatments and their side effects is a prerequisite to providing not only the best medical treatment and follow-up, but also to providing skilled physical and psychosocial supportive care in all stages of cancer care, including palliative care. While the extent of knowledge required may vary among the disciplines according to their roles, information about current treatment and its related aspects was a widespread need.

Adequate, applicable current knowledge is needed to deal with cancer patients' problems at the district level where specialized resources are limited (e.g. treatment of emergent treatment complications, managing nutrition related side effects in chemotherapy patients).

Specialists and some pharmacists stressed the need for treatment and/or follow up guidelines and protocols. The Internet was viewed by some physicians, pharmacists and nurses as a way to improve access to guidelines and/or protocols.

Topics of interest across several disciplines included: new and current treatments, oncology pharmaceuticals (chemotherapy, pain, and other mediations used in symptom relief), dealing with treatment side effects, and pain & symptom relief. The data also suggested positive attitudes toward multidisciplinary approaches, especially with respect to pain and symptom management.

Navigating the system An understanding of the cancer care system and how to navigate it is a treatment-related educational need. This included an understanding of the patient's treatment 'road map' and their experience at the cancer centre.

Available Resources & Team Members' Roles Every focus group highlighted professionals' knowledge gaps concerning resources for patients. Another prominent learning need was increased knowledge about what resources exist and how to access them. Parallel to this was a strong interest in knowing more about other team members' roles and areas of expertise and how they could contribute to patient care. This need was expressed across disciplines, often by physicians. Some participants clearly articulated they wanted to be able to direct patients to community resources, but lacked the information to do so. Variable knowledge appeared to exist in some groups about the toll-free Cancer Information Service, one accessible source of resource information.

Other Learning Needs Several other learning needs were raised in the group discussions, e.g. Screening, Diagnosis, Patient Communication ('Conveying Bad News' and End of Life Issues), and Psychosocial Care. Although not as prominent, they were important to some participants and their perspectives are contained in the full report.

Learning Preferences

Barriers to CE Participants identified significant resource barriers to continuing education (CE), including insufficient human resources to relieve potential CE participants, the amount of time available to attend, and funding issues such as income loss for physicians and lack of paid educational leave for other health care workers.

Short, locally delivered sessions In the context of significant barriers to participating in CE, there was strong preference expressed for short sessions, delivered locally and/or regionally and planned with sensitivity to local conditions. Videotaping, and multiple continuing education delivery mechanisms may be required to reach participants given the resource and time constraints.

Local resources There was some recognition that local expertise and resources were underused with respect to continuing education. The underlying themes of human resource and time limitations suggest that current capacity to engage local resources in delivering intensive continuing education efforts may be limited. This would need to be explored further at a district or regional level.

Case study format Specific formats for continuing education were explored differentially among groups. Case study approaches, while not extensively discussed, when they were addressed received significant attention and positive appraisal. First hand reports indicated that even in a simple form (such as a case based scenario accompanying a patient discharge summary), case study materials facilitated a multidisciplinary approach to care. The significance of the case study method rests also with its adaptability to a variety of delivery mechanisms and formats, including print resources, inservices, study groups, the Internet, Telehealth and workshops. This is important since no single method received universal support among participants, consistent with the view that different people with different learning styles will prefer different formats.

No clear preference emerged regarding continuing education delivery methods. As a continuing education program delivery method, ***the Internet*** evoked a mixed reaction, with convenience and level of interaction appearing as some of the factors influencing its acceptability. Its potential use to disseminate standards of care and protocols was evident, although some indicated print resources may be required because of access barriers. Several participants also wanted to be able to direct patients to reliable web sites.

Telehealth also received mixed reviews, with improving access a perceived benefit to some, in the context of geographic and resource constraints. Nurses frequently mentioned videotaping of Telehealth sessions for viewing at more convenient times. Two major limitations surfaced: videotaping restrictions (affecting access to the information) and the degree of interaction Telehealth affords. Data suggested these barriers could be at least partially overcome by centrally located videotaping and skillful facilitation with appropriately sized groups.

Interdisciplinary Continuing Education appeared to be endorsed in principle by some participants, but its acceptability would depend to some extent on the topic. Palliative care was viewed positively and emerged most clearly as a suitable topic for interdisciplinary education. This implies it may be an appropriate model to examine if planning education on other topics. Data suggested the following elements may be important aspects of palliative care interdisciplinary education: a clear patient care focus, a recognized need for shared expertise, and an opportunity for team building incorporated into the educational processes. Other topics were suggested for interdisciplinary education, but there was insufficient data to assess their appeal. They included pain and symptom management, dealing with the patient holistically or as an individual, ethical issues, and community resources. Groups under explored any problems that might exist concerning bringing together the different disciplines.

Working with the Cancer Treatment Centre

Although the main purpose of the focus groups was to examine cancer educational needs, communication, coordination and relationship issues with the cancer treatment centre were raised in most groups, and appeared to be an important theme.

It should be noted that some participants perceived poor communication and coordination as a system wide issue that also exists at the local level, and not only in the relationship with the cancer treatment centre. (Communication issues also were reported with reference to Moncton cancer care services used by some patients in District 5.)

Communication issues with the cancer treatment centre were identified in all but one focus group. While different groups described various aspects of the problem, this concern was extensively and sometimes intensely expressed, sometimes with strong agreement within groups.

Poor flow of information from the centre, including untimely reports, was a significant observation of several physicians, other team members, and members of patients' families. It is noted that there was one report that information flow has shown improvement. Several impacts of lack of information were described. Sometimes district physicians do not have up-to-date knowledge of the patient's condition and treatment, yet they may still have to provide care for patients with urgent complications or for other medical problems with these information gaps. Sometimes they have to rely on patients for information. Without information and up-to-date knowledge of current treatments, health care providers are sometimes unable to answer patients' questions. Support was expressed in some groups for a patient-carried record as one solution.

Difficulties providing follow-up at the district level were reported, with respect to untimely communication and insufficient communication on protocols.

Lack of coordination with the cancer treatment centre was another identified issue. Coordination problems with respect to follow-up were articulated. Delays, duplication or missed follow-up were described. A 'road map' was suggested, more clearly defining roles and responsibilities in patient follow-up.

There was also a perceived need among some participants for an increased awareness and understanding on the part of the cancer treatment centre with respect to district expertise, the patients' environment, available district resources and their limitations.

Communication, coordination and team work problems have other intangible aspects. Perceived poor communication may contribute to a sense that the patient is "taken over" by the centre, and in some cases, that district level expertise is undervalued.

Other Systemic Issues

Facilitators, after conducting the first two groups, identified that discussion concerning systemic issues was consuming significant amounts of time. In order to re-focus participants' attention on the continuing education questions, the groups were restructured to limit discussion on systemic issues. Nonetheless, participants made frequent references to the inter-related barriers of funding, human resource and time limitations. These systemic issues posing barriers to cancer care remained an underlying theme in other discussions overall, although different groups dealt with different aspects, and had different opportunities to explore issues.

Human Resource & Time Constraints Participants described how human resource and time constraints can pose barriers to treating and caring for patients, affect the implementation of a multidisciplinary approach, and reduce opportunity to participate in continuing education. Some specific gaps in palliative care services and resources were raised in several groups including resource and policy barriers to delivering palliative care in long term care.

Financial Burden of Cancer The financial burden of cancer experienced by patients was another systemic issue of concern to several participants, especially with respect to funding medication coverage for patients at home and those with incomes above the $15,720 cut off.

Access issues emerged in some groups, especially with respect to geographical barriers and transportation difficulties for older patients and those with lower incomes. Distance and time away from home may be other factors affecting patients' decisions regarding treatment. There was some support for more chemotherapy and follow-up closer to home to relieve patient burden.

District Cancer Care Program Model

Findings are restricted to four groups, with three of these groups having opportunity to explore both the overall concept and the medical coordinator role. Only a few individuals across the four groups indicated some knowledge of the proposed program. In subsequent groups, questions on this topic were eliminated because previous participants were generally unfamiliar with the concept.

Funding Concerns Some support for the concept of district cancer care was apparent, both explicitly stated with respect to the topic and implicit in the context of other discussions concerning access to treatment (chemotherapy) and follow-up. However, funding concerns were a predominant theme, with a strong perception that the district cancer care will require new funding, that existing budgets and resources cannot accommodate the further strain anticipated with a shifting of cancer care to the districts. There was also concern that districts may be made to assume care without the necessary new resources to make it achievable and with negative impact, i.e. 'shrinking' of existing resources. Lack of support for this approach was evident.

The medical coordinator position was perceived to require new funding. Some questions were raised regarding the role, and the family physician's involvement. Separation of clinical and administrative functions were also recommended.

Limitations

The qualitative findings are specific to the participants and groups involved and are not generalizable in the quantitative research sense. Findings may not completely portray all themes or significant factors related to a specific topic. Breadth and depth of discussions varied across groups, and some groups had differing opportunities to explore some issues. Despite the limitations, the findings do offer information that can assist in understanding how participants, in their contexts, view some aspects of continuing education related to cancer care and the delivery of cancer care.

Discussion

The focus group findings, based on multidisciplinary perspectives, highlight the interrelationships between continuing education, cancer care delivery, and systemic contextual factors. These factors include resource limitations, geographical barriers, and cancer care system communication and coordination problems. The interrelationships suggest for these participants, that updated cancer cancer knowledge will be acquired and used more easily and effectively, if systemic issues are addressed simultaneously. Knowledge related to treatment and resources for patients may have a synergistic potential to facilitate "seamless" patient care if system wide communication and coordination is improved. Interdisciplinary education may also play a role in this respect, particularly for appropriate topics or areas that are conducive to multidisciplinary approaches. The significant resource barriers that constrain the delivery of health care in the districts will need to be considered in planning new models of cancer care delivery and continuing education initiatives.

1.0 PARTICIPANTS

1.1 Participants by Discipline

A total of 98 health care providers participated in 10 multidisciplinary focus groups, approximately two hours in length. Groups were held in the 9 Nova Scotia district health authorities (two groups were held in Capital Health), between April and June 2002.

Nurses, physicians and pharmacists comprised 78% of participants overall, with 8 other disciplines contributing the remaining participants (Table 1). Overall, there were 8 community-based specialists and 10 general practitioners or family physicians. Two of the family physicians have special interest in palliative care. The nurses practiced in a variety of settings, including ambulatory care (including chemotherapy and diagnostic services), acute care, palliative care, home care, the community and long term care. Community (retail) and hospital pharmacists also attended. Ten per cent (10%) of participants indicated they had interest in cancer care aside from their immediate health care provider role. Four participants disclosed personal or close family experience with the cancer care system, and seven were active as volunteers (health care, cancer care, and palliative care related governing boards or in volunteer roles involving direct cancer patient or public contact). One participant was a lay person active at the board level in the voluntary sector.

Table 1 Total Number of Participants by Health Care Affiliation

Professional Affiliation	No.
Physician	18
Nurse	44
Pharmacist	14
Dietitian	6
Social Work	6
Spiritual Care/Chaplain	2
Volunteer Coordinator	2
Technologist	2
Other*	4
TOTAL	98

*includes physiotherapy, management, volunteer

1.2 Group Composition & Size

All groups were multidisciplinary, with six groups containing five different disciplines, and four groups containing four disciplines. Nine of ten groups contained at least one physician, with 6 groups having two or more. Professional practice specialties and settings differed within disciplines across groups, creating more heterogeneity.

Homogeneity is usually recommended for focus groups to facilitate comfortable discussion among compatible participants, with heterogeneity appropriate in instances where interaction between groups is an area of interest.[1] In this case, the interest in district cancer care models and interdisciplinary education appears to support the use of heterogeneous, interdisciplinary groups. The respectful sharing of information and friendly banter among participants suggest that participants were comfortable enough with each other to engage in the discussions. Nonetheless, it is still possible some participants, in the presence of others possessing different power and authority within their working relationships, may not have felt comfortable to freely comment on continuing education needs or system barriers they may perceive either within or outside their own discipline.

Groups ranged in size from 6 to 13 participants, with 6 groups having 10 or more participants. The number of participants was appropriate for the nominal group process but was likely too large for optimum use of the focus group method. Groups of 6-10 participants are recommended[2]to allow participants adequate opportunity to discuss topics.

2.0 QUESTION GUIDE

The original interview guide attempted to elicit data on several important, often complex topics and was somewhat lengthy. After the first two groups, the group format was modified to include a nominal group process in order to focus more on the continuing education needs and learning preferences and less on the issues and barriers in providing cancer care in the districts (Suzanne Ferrier, personal communication). A second change was also made. The original question guide included items on a proposed leadership model for district cancer care and the use of a part-time medical coordinator. Questions pertaining to this area were removed from the guide, when it was found that participants in the first four groups, with a few exceptions, were generally not familiar with the proposed model.

3.0 METHODS OF ANALYSIS

Transcripts of the taped focus groups were verified by the analyst before importing into NUD*IST 4[3] for data management. When necessary, a facilitator was consulted to interpret any potentially significant portions that were unclearly taped and incompletely transcribed.

Data were systematically coded; that is, broken down into meaningful units and assigned to categories in 'index trees' that were initially structured according to interview guide and developed further as new categories emerged from the data. A constant comparative approach[4,5] (e.g. within and between categories of data) was used in the interpretation, aided by matrices[6] constructed to facilitate comparisons within and between disciplines and districts. Negative cases (instances that did not appear to fit patterns in the data) were identified, and alternative explanations were considered.[7] Themes were identified and interpreted.[7] Findings were further synthesized in the report writing process.

3.1 Trustworthiness of the Findings

Several measures were employed in the analysis to ensure credibility and trustworthiness of the qualitative findings.[8,9] A systematic analytic approach was used, as previously described. An audit trail comprised of the transcripts, coding reports and matrices permits confirmation that the findings arise from the data. Analysis was conducted by a person with a health and adult education background, and experienced in qualitative research. Credibility was further enhanced through review of findings by the three group facilitators/observers.

4.0 EDUCATIONAL NEEDS

Discussion data from the nominal group process and other portions of the group sessions were combined in the analysis pertaining to educational needs. (Voting results for the nominal group data were analyzed separately). Educational needs were described.

Limitations: Some topics were variably explored across groups. This may reflect the interests of the participants and the amount of time available for discussion, given the length of the question guide. As well, the round robin format used in the nominal group process emphasized collecting all possible topics without repetition before a voting procedure. This approach may cause participants to withhold their own views or explanations if 'their' topic was already cited. This limits the variety of perspectives and rich description that might be gathered on a particular topic.

Prominent Educational Needs:

- Updated knowledge about treatment, and management of treatment side effects, pain and other symptoms. (Section 4.1)

- An understanding of the cancer care system and how to navigate it included an understanding of the patient's treatment 'road map' and their experience at the cancer centre. (Section 4.2)

- Increased knowledge about available resources, and how to access them for patient care. Every focus group highlighted knowledge gaps concerning resources for patients. (Section 4.3)

- Increased knowledge about other team members' roles, expertise and how other team members can contribute to cancer patient care. This need was expressed across disciplines, often by physicians. (Section 4.4)

- This participant's comments captures the prominent educational themes:

  > "I would I think, I as a physician, need to be educated by specialists who are doing that kind of work as to what the new treatments are, what's appropriate, when to do this and when to do that. But at the same time, I'm lost when it comes to knowing, you know, what's available in the community. What's available to people who have cancer, who you're working with and how you're going to either…so there's a whole big education there that we have to…I think, for physicians to understand we're part of a team and we need to know who's on the team" (physician)

- Other educational needs also were identified e.g. Screening (section 4.5), Diagnosis (section 4.6), Psychosocial Care (section 4.7), and Patient Communication (section 4.8), including 'Conveying Bad News' and 'End of Life Issues'. While not as prominent overall, these needs appeared important to the group members who discussed them.

Descriptive information on both higher and lower priority educational needs is presented below.

4.1 Treatment & Follow-up

Education on current cancer treatment, including pain and symptom management, was a strongly voiced need, extensively expressed among disciplines and groups. Physicians, both specialists and general practitioners, nurses in many practice settings, and pharmacists spoke of needing to update their knowledge, as treatments have advanced and changed. Participants described how knowledge of treatments and their side effects is a prerequisite to providing not only the best medical treatment and follow-up, but also to providing skilled physical and psychosocial supportive care in all stages of cancer care, including palliative care. Adequate, applicable current knowledge is needed to deal with cancer patients' problems at the district level where specialized resources are limited (e.g. treatment of emergent treatment complications, managing nutrition related side effects in chemotherapy patients).

While the extent of knowledge required may vary among the disciplines according to their roles, information about current treatment and its related aspects was a widespread need.

Specialists and some pharmacists stressed the need for treatment and/or follow up guidelines and protocols. The Internet was viewed by some physicians, pharmacists and nurses as a way to improve access to guidelines and/or protocols.

Topics of interest across several disciplines included: new and current treatments, oncology pharmaceuticals (chemotherapy, pain, and other mediations used in symptom relief), dealing with treatment side effects, and pain & symptom relief. The data also suggested positive attitudes toward multidisciplinary approaches, especially with respect to pain and symptom management.

4.1.1 The Latest and Most Effective Treatments

Across disciplines, many participants expressed they wanted to know what "the best practices" and "the cutting edge" treatments are for cancers. They also want easy access to information resources about cancers, their treatment and prognoses. Some participants strongly articulated they *and* their colleagues needed updates. Participants, according to their disciplinary role, had different interests but overall, a knowledge of current cancer treatment and its various aspects was a widespread need.

> "I think there's a general lack of knowledge, among physicians, you know, I certainly feel it..." (general practitioner)
>
> "...most people here need an update on different types of cancer, particularly those that are prevalent in our area, and what treatments are available, and the different complimentary therapies that might be appropriate" (nurse)

> "...we need someone to stand there and tell us [...] 'this is what's current, this is what we know, this is what you can do' We're out there flogging away in our offices, you know it's catch is, catch can...You could go into a doctor who doesn't, who hasn't even heard of some of this stuff [i.e. markers, BRAC gene]" (general practitioner)

- Current knowledge has obvious implications for patient treatment, as the previous comment infers. Further, a specialist in another group indicated that patients may not be receiving the best combined treatment approaches because some specialists lack education. From a family physician's perspective, confidence in the consultant's knowledge can be a concern, as presented below:

> "...knowing I suppose. [...] from a family doctor's point of view, knowing that you're getting the best advice from your consultants. I mean, we're not the only ones who are in the dark on things. I mean, you know, the specialists may be in the dark...I guess with access to up-to-date knowledge from people who know what they're talking about and right on the leading edge, then we would feel secure." (physician)

- Health care providers in their disciplinary-specific roles want to be able to answer their patients' questions about the treatment process and its effects knowledgeably and supportively. To do so, they need information about the types of cancer and their current treatment approaches.

> "Well, I've got a big one...I would like easy access to [...] up-to-date current treatment guidelines for the various cancers. Because, I mean, the average GP...you know, you get a couple new cancer diagnoses a year, and like, especially the less common ones, you may only deal with one or two in your entire practice lifetime. So you've got these patients, and well you just feel stupid, right? They're asking questions and you're saying, 'well, see what the specialist says', when they see them in three weeks time. And you know. 'Am I going to loose my hair?' I mean, a bunch of things. It would be nice to at least have an Internet site..."This is the most likely thing that would happen,' you know. Or a 1-800- number..." (physician)
>
> "I'd like to see more education on treatment from a nursing perspective, to help clients. [...] I don't have a lot of answers to their questions on the medications because they do change and I don't know the current..." (VON nurse)

4.1.2 Guidelines, Protocols and Standards of Care

Several participants, especially physicians and pharmacists, emphasized knowledge of and access to treatment guidelines, treatment protocols and standards of care. Sometimes these terms were used interchangeably.

- Specialists involved in treatment wanted to know current protocols. A few indicated they wanted to be better informed about research protocols. Physicians may be confronted with patients experiencing treatment complications and may lack the up-to-date information that guidelines and protocols offer.

> "I'm very comfortable with making the diagnosis, staging the patient and giving the chemotherapy without any reference to oncology in Halifax, whatsoever. But, I'm not sure I'm using the latest or most effective protocols. It's very difficult to access in the literature exactly what drugs and what doses of those drugs should be used[…] (specialist)
>
> "…the current standards or guidelines specific…it would go under the same thing [treatment updates]. And maybe along with that, if there are new research protocols or protocols that might be started–many of those are actually started in Metro, and we often, unfortunately are the last, well not always the last, but close to the end to hear about it." (another specialist)
>
> "Well, if they [family physicians] see a patient on a Saturday morning in outpatients in [**** Hospital], and they don't know what the protocols are, and are not available, they really are flying; and that's an educational issue." (another specialist)
>
> "We could benefit from some guidelines for the provision of care" (palliative care consult pharmacist)

Easy access to guidelines and protocols is an important aspect. Some participants reported difficulty locating or obtaining protocols, which are also subject to change. Internet access was advocated by some (see also Internet 5.6.1).

> "If we could have access to that, I think it would have to be Internet based, where I could sit down in my office and say, 'okay, "I've got a patient with X stage of some malignancy, and I want to know first of all, when to refer and who to refer to, all of that. Family physicians needs this, as a specialist in a rural community, I need this." (specialist)
>
> "Protocols change so rapidly and if you know where to go and look for the information, it's very useful." (community pharmacist)

4.1.3 Chemotherapy

Several physicians, pharmacists, and nurses in a variety of practice settings expressed interest in increasing their knowledge about chemotherapy and other medications used to treat its side effects, and accessing protocols.

- Applicable knowledge to deal with chemotherapy side effects was emphasized. This was stated outright in one group, with general group agreement indicated. Comments in other groups concerning symptom management tend to support this emphasis.
- A hospital pharmacist suggested the QEII pharmacy provide inservice support to peripheral hospitals regarding safer chemotherapy preparation techniques.

4.1.4 Pain & Symptom Management

Learning needs in this area encompassed cancer symptoms, treatment of side effects and palliative care. While chemotherapy side effects were identified by several participants, there was scant information specific to radiation side effects.

Pain Management:

- Most groups contained some discussion related to pain management in treatment and palliative care.

- General interest was verbalized in several groups, with more detailed information offered in only a few sessions. Pain management would appear to be an obviously important issue in cancer education. However, there was little discussion of the issue in comparison to the weight assigned in the nominal group process voting. This may reflect the constraints of the nominal group process and/or lack of probing by moderators. As well, the issue may be so obvious to participants they may not have felt compelled to describe their needs in more detail. Possibly, some were reluctant to describe their own knowledge deficits in a multidisciplinary setting.

- The more in depth data revealed that although some participants described positive changes in pain management practices, it remains an educational issue that crosses disciplinary lines. A patient and family education component was also identified. Education aimed at changing physicians' ordering practices and improving nursing approaches were suggested in a few groups. However, pain management is a complex educational issue as the following quote illustrates:

  > "…there's nurses who are reticent to give regular, larger doses, there's families and patients that don't want to take it because it's a narcotic and they're going to get addicted to it and their grandmother told them they shouldn't, and there's people who can't take it because they get constipated, and if only for a change in their diet and the addition of some bulk agents they could take it…it crosses all the barriers and I think it's…The education for that particular problem of cancer care is huge." (physician)

Other Symptom Management:

- Medications: Physicians, pharmacists and nurses expressed interest in increasing their knowledge concerning pain and other medications (e.g. anti-emetics and "magic mouthwashes").

- Nutrition: Some nurses, dietitians and pharmacists expressed a need for more nutrition information, especially to assist in counselling patients with disease symptoms or treatment side effects. Providers encounter patients who cannot afford standard nutritional supplements (e.g. Ensure) and alternatives are needed. The range of possible topics of interest was not explored in depth, but the following specific areas were suggested by individuals: appetite changes, nutritional supplements, weight loss and weight gain (the latter associated with breast cancer treatment).

> "So you know, I need more hands-on stuff that I can tell somebody right off the bat, or the person who is looking after them, because it takes so long to get into a dietitian or someone along that line." (chemotherapy nurse)

4.1.5 Lines & Pumps

Caring for portacaths, PICC lines, Hickman lines and CADD pumps were identified as continuing education needs especially by nurses in acute care and community settings, in both metro and peripheral areas. A physician and a laboratory technologist also verbalized interest.

4.1.6 Complimentary & Alternative Therapies

Information needs in this area were expressed by individuals in six groups, with some confusion in use of the terminology apparent. Some providers reported receiving questions from patients, and have encountered patients using various therapies, such as shark cartilage. Application of complimentary therapies by palliative care volunteers is being explored in at least one district. Participants' interests included: the different types of therapies, their pros/cons, and nutritional aspects.

4.2 Navigating the System

Discussion occurred in all ten groups concerning various aspects of patients and professionals 'navigating' the cancer care treatment system. Professionals from several disciplines described how patients feel "overwhelmed," are anxious, do not know or understand what will happen next, and have many questions that front line professionals are sometimes unable to answer. Learning needs with respect to navigating the cancer care system emerged, and focused on understanding both the patient's treatment and their cancer centre experience. The analogy of a 'road map' to anticipate what is ahead for patients was evoked, as described below.

- A Road Map: 'Understanding What's Ahead for Them' was a theme expressed in several groups. Professionals across many disciplines articulated that they needed a better understanding of the cancer treatment and the cancer centre experience. Front line health care providers expressed a need to be able to answer some of their patients' questions, and direct the patient to appropriate resources, both at the cancer treatment centre and locally. As one community pharmacist said, "you become the navigator because nobody else is available."

> "I think a lot of times, you know, they're referred off and really, they go down, they see us and come back, and the family physician is still sort of wondering just what there people went through [...]. The actual process of what happens with this patient once he gets into the system of the cancer centre." (community specialist)

> "...we all need to know ourselves where to direct patients. And right now, for me, I can't always answer those questions, and I'd like to know what resources there are." (acute care nurse)

> "[referring to a Nursing Oncology Day at the QEII]. It really opened my eyes to what out patients face when they go up there [...] I mean, what I knew for

> radiation was 20 some years ago; it certainly has changed a lot, and what is it like to go to chemo, and cancer treatment. All those kinds of things. Like it kind of opens our eyes too, to see what's ahead for them, and makes you a better person to explain to them what is going to happen." (palliative care nurse)
>
> "…we need information on how to help people know how they're going to navigate through the system, what it is they're going to navigate. You know, even the road map, number one." (VON nurse)
>
> "…we've had palliative care come and speak to us […] So, now we know where the patient has been through just [with] palliative care, but I would like to see where they have been before…" (community pharmacist)

- Support for the navigator position or concept was evident in several districts, as a resource for patients, families, and health care providers, and serving as a link to the cancer treatment centre.

4.3 Available Resources and Supports

All focus groups highlighted the need for health care providers to know about available resources and how to access them. This was a prominent need, extensively expressed among physicians, nurses, social workers and community pharmacists. Some participants clearly articulated they wanted to be able to direct patients to community resources, but lacked the information to do so. Variable knowledge appeared to exist in some groups about the toll-free Cancer Information Service, one accessible source of resource information. Parallel to the need to know about resources was a strong interest in knowing more about other team members' roles and areas of expertise and how they could contribute to patient care (Section 4.4).

- Professionals' and patients' lack of knowledge is a barrier to patients accessing needed services and resources, including those available from other team members. e.g.) patient navigator services, psychological support resources, Canadian Cancer Society services, cancer information resources, financial support, and supportive care such as VON, home care and palliative care.

> "One of the problems I have with communication is even more basic […] it's knowing what's available in the community for the patients. And I find that even on that basic level, for some reason, I don't ever seem to know what's going on." (physician)

- Positive attitudes were expressed toward directing patients to resources and services but participants need to know what is available where, when to direct patients and how to direct them.

> "There's a lot of confusion [about] who covers what and what the availabilities are and who actually qualifies for them" (home care nurse)

- Several participants indicated incomplete knowledge of local resources. Sharing of information occurred in some groups, further demonstrating educational needs in this area. Some participants commented on the need for more knowledge about regional and district resources both at the local community level and at the cancer treatment centre level.

> "…we were talking about Halifax knowing about the resources that are in…not in our area. And I was thinking, even within our own area, a lot of people don't know the cancer resources that we have here…" (palliative care nurse)

- Some group discussions revealed variable knowledge concerning the toll-free Cancer Information Service, an accessible source of information about cancer care resources.

4.4 Interdisciplinary Team Work: Others' Roles

Most groups discussed various aspects of team work, such as knowing more about other team members' roles, and the value of and need for improved team communication. There was broad interest in what other professionals know, and how their expertise contributes to patient care. This was expressed across several disciplines, and often by physicians.

> "I think everybody on the team needs to have a flavour of the other disciplines, I mean it's part of the education, it's part of the team building process. So I know what your role is, you now what my role is, but I also know when I see a patient at home on this drug that 'oh, there may be a couple things going on,' so I come back and tell the right people." (nurse)

> "…it is good for the rest of us to know what these other groups know. For example, well again to use pharmacy, it would be good for me to know that the pharmacist knows which ones are toxic when you spill them on the floor and not to wipe it up with a paper towel, so that I would know who to call if I dropped it on the floor. So you still have to know what it is that they know, but you don't have to know as much as they know." (physician)

4.5 Screening

4.5.1 Screening Recommendations and/or Guidelines

The need for more information was raised in most groups, especially among physicians, nurses and pharmacists, and most often regarding breast, colon, and prostate cancer. Three groups provided scant or no information on screening needs.

- Physicians' learning needs: Some general practitioners specified information on screening programs generally, but especially breast cancer, risk/benefits of mammograms for women age 40-50, the "true benefits" of screening and cost issues, fecal occult blood, colon and prostate screening. Physicians are faced with some areas where there are "no hard and fast rules" perceived (e.g. colon cancer), changing guidelines, different guidelines from different sources, and some controversies (PSA, BSE). The following dialogue highlights some of these issues:

> "I think I'm speaking for family doctors, I don't like to say I'm speaking for all of them, but further education on the breast cancer program and breast screening for women, and guidelines. (physician)

> It seems to depend on what you read. (unidentified speaker)
>
> Oh doesn't it. And everybody has a little system in place because it changes, but… (same physician)
>
> And also with pap smears… (unidentified speaker)
>
> Well, yeah, but I put breast, but really any of the screening…colon cancer, prostate, even screening programs; a general consensus or as close as one can get, that everybody is doing the same thing. (same physician)"

Participants were not systematically asked to assess screening learning needs according to specific cancers. Some data concerning colon cancer screening suggests variation in knowledge levels among districts. A surgeon in one district reported some patients with positive family histories who were diagnosed with cancer had not received screening advice from their family doctors. In another location, another surgeon reported family physicians were well educated about colon cancer screening.

- Nurses' & pharmacists' learning needs: Some professionals identified a need to know information on screening recommendations and resources in order to inform patients and/or their families and to encourage screening uptake.

> "I don't think it has to all fall on physicians. I think if we were all more knowledgeable, then we'd be better equipped to teach, not just my palliative patients, but their families about the options that are currently available. And that's something that I don't currently have a lot of information about to be able to teach you." (palliative care nurse)

- R.N. Pap Pilot Program: Nurses working in this program were reported to have specific needs related to anatomy, physiology, the pap procedure and slide preparation, and reaching under served populations. Lay educators require more adult education training, according to a program representative.

4.5.2 Screening Issues

- Patient and Public Education: Several participants across five groups commented on this topic. Some identified lack of patient and pubic knowledge about risks and screening as a barrier to screening. It was noted the public is likewise faced with unclear guidelines and conflicting media reports. Some data indicated existing patient resources (e.g. Health Canada breast cancer brochures) are not always being made available to patients. Physicians in two groups commented on the need for realistic public expectations with respect to screening and its impact.

- Patient Beliefs and Attitudes: Some participants identified some people believe cancer can't or won't happen to them, and therefore don't seek screening. It was observed some patients, particularly men, may not seek screening for colon or prostate cancer for reasons of embarrassment or discomfort, unless the physician introduces the topic.

- Access Issues: Approaches to reach under served female populations were discussed in Colchester East Hants, Cumberland Health and Cape Breton District Health Authorities with several positive references made to the Well Women's Clinics that combine community lay education and outreach, women's health information, and cervical screening by female RN providers. Some physician resistance was reported in one location where female physician providers were available.

  In Colchester East Hants Health Authority, there was interest in bringing the breast mammography clinic to the community.

  > "Yeah, it's something they've go to do, but they figure, 'well, you're close enough to Halifax, you don't require that', but really there still was a need." (nurse)

- Costs & Resource Limitations: Physicians in two groups raised the need to 'realistically' appraise the cost issues, such as the amount of a resources available to follow screening recommendations, the actual costs of preventing one death, and the psychological costs associated with false positives (e.g. mammograms).

  > "You know, the United States produces this wonderful recommendation for screening and you know, they come up here and [it] hits us, and you just look at it, you know...bankrupt the entire system! [...] I mean they say, 'do this' and if everybody did, that the ship would sink..." (specialist)

- A shortage of gastroenterologists was noted in South Shore Health, and long waits for GI diagnostic assessments in Cape Breton District Health Authority. Other resource shortages may exist but were unreported. Reference was also made to many people not having family doctors, inferring a shortage affecting patients' access to screening procedures.

4.6 Diagnosis

4.6.1 Newest & Best Available

Learning needs pertaining to diagnosis were not extensively discussed among groups, but were clearly of significance to the physicians who wanted more knowledge in this area. These physicians succinctly stated they want to know about the newest, best, most effective and most economical diagnostics available. A few physicians, in expressing their desire for the newest diagnostic knowledge, described the emotional burden associated with making a cancer diagnosis. One specialist described the stress of sometimes wondering, "Am I guilty that the patient has not been diagnosed earlier?"

4.6.2 Public Education: Cancer Signs & Symptoms

Participants across several disciplines in half the groups recommended public education on cancer warning signs and symptoms, with some making specific reference to the 'seven signs' to prompt earlier physician assessment.

> "...from what I hear from patients, the complaints have been left too long." (chemotherapy nurse)

4.6.3 Pharmacists' Role

While mentioned only once, a potential role for pharmacists was articulated. A pharmacist identified as a learning need knowing how to and when to recommend physician assessment.

> "I know of several situations where probably the pharmacist would have been the only person who really had a lot of contact with that patient before they finally progressed. I think we need more and more, to be able to say when, really more confidently, 'you should go see your doctor, this is very concerning.'" (pharmacist)

Another person creatively suggested that others outside the health system, such as barbers and hair stylists, be targeted with information since they may observe skin changes in their clients.

4.6.4 Diagnosis & Treatment in Long Term Care and Elderly Patients

Some discussion on cancer diagnosis and treatment in long term care and/or aged population emerged in three groups. A director of long term care commented that patients in long-term care may not receive a 'holistic' diagnostic approach. Treatment for single symptoms may result in cancer either missed or not followed up correctly, this having negative implications for symptom relief (expressed by nurses in a few groups). Communication barriers presented by dementia also makes diagnosis more difficult. Physicians in one group expressed interest in age and treatment issues.

4.6.5 Patient Preparation for Diagnostic Imaging Procedures

From a diagnostic imaging perspective, patients are sometimes not adequately prepared for tests, resulting in delays. Patients' understanding of procedures involving contrast media was a particular concern. The data does not indicate if this is a widespread problem, or to what degree it is related to professionals' lack of knowledge about the procedures, inadequate patient education or other factors.

4.7 Psychosocial Care

All groups contained some reference to psychosocial care. Learning needs included understanding the patients' needs and emotional responses and being able to provide support.

- Data suggests that providing support at the time of diagnosis and at end of life can be challenging for some professionals.

- Participants with pharmacy, diagnostic imaging and laboratory technology perspectives indicated there is need and interest in increasing understanding about the patient's experience in order to react to the patient more supportively.

- While comments suggested communication is an integral part of providing emotional support, knowledge of current cancer treatment can also be important, as this physician explained:

  > "See from my point of view as a doc in the community, I would see a role for myself and with my patient, in trying to interpret some of that for my patients and maybe providing some of that touchy-feely stuff that you don't get at the clinic. But I can't do that if I don't know what the hell is going on!" (general practitioner)

- Some groups indicated they were uninformed about available supportive resources for their patients, and this a barrier to providing psychosocial care. Participants wanted to know what options existed for their patients and how to access the resources. This is discussed further section 4.3 Available Resources and Supports.

4.8 Patient Communication

Most of the groups explored some aspects of patient communication, particularly "Conveying Bad News" and "End of Life Issues."

4.8.1 Conveying Bad News

- Communicating bad news such as a cancer diagnosis or prognosis is a complex, multi-factorial issue, as group discussions revealed. These are times when patients need support.

- There were reports in a few groups that patients sometimes are not told their diagnosis. Family requests to 'not tell' are also encountered. How widespread a problem 'not telling' is cannot be determined from these data. In depth discussion in several other groups affirmed that patients are in fact told (sometimes more than once), but they do not necessarily take in or understand the information. This appeared to be a significant issue that challenged physicians and nurses. Some possible factors described by participants included: patient denial, patients feeling overwhelmed, not understanding the language used, low literacy, and patients misinterpreting the information (e.g. "successful" palliative radiation therapy becomes "cured"). A physician related that is difficult to communicate to the patient that there are "different levels of the disease."

- Several participants, especially nurses, described how patients seek help to interpret the information received from physicians. A nurse navigator termed this "re-telling the diagnosis."

- A physician in another group summarized the learning needs with respect to communicating 'bad news' twice in the focus group session:

  > "I think we all need to have better education skills in how to deal with bad news and how to present bad news, convey in a way that it's retained, and the outcomes of having given bad news." (general practitioner)
  >
  > "I would like to see nurses have more skills in presenting the bad news and dealing with it. Because often what happens is the physician conveys the news,

> and the patient asks the nurse to interpret it again, or maybe give it to them because maybe they didn't understand what the doctor said in the first place. Or the doctor never told them and the nurse is the one who ends up giving the bad news and then dealing with it. And I think it is very common" (general practitioner)

4.8.2 End of Life Issues

- Talking to patients about end of life issues (e.g. palliative care decisions, living wills, power of attorney, other arrangements) was raised in half of the groups. Some physicians, nurses and social workers wanted information on how to approach the patient and discuss these sensitive topics.

- Several participants from one group agreed that end of life issues generally were handled well in their district. Some data suggested that lack of team communication and coordination was a factor in another district where less satisfaction with handling this issue was expressed.

- Dealing with the dying process and needing education to help patients who are preparing for dying were other identified educational needs not extensively discussed.

4.9 Palliative Care

There were relatively few discussions about palliative care educational needs per se. This may reflect time constraints (near end of the section in the question guide), and the process. Some aspects of palliative care, such as pain and symptom relief were discussed as part of treatment issues, often with contributions from palliative care and VON nurses.

- There were statements in a few groups advocating information about palliative care should be provided to all health care providers in contact with patients, with the goal of increasing understanding of the patient's experience and comfort. One participant advocated that diagnostic imaging personnel are an appropriate target audience.

End of life issues as learning needs are discussed in section 4.8 Patient Communication.

4.10 Prevention

Professionals' own learning needs in this area were not extensively discussed. This may reflect participants' specialties and their scope of practice with respect to prevention. Nonetheless, group interaction indicated there was significant interest in a variety of prevention-related issues among participants and across disciplines.

Public education: The two groups exposed to the original interview guide were asked to comment specifically on prevention, wherein an emphasis on public education emerged. Four other groups also indicated support for prevention education. Public education was advocated in these areas: prevention of smoking-related cancers and skin cancers, healthy diets and healthy lifestyles. Several participants agreed children and youth should be identified targets.

Professionals' learning needs: The following prevention learning needs were raised by individual participants, some of whom stressed they wanted information based on evidence and consistency in the messages so everyone is teaching the "same thing".

--smoking cessation (physician)
--skin cancer (nurse)
--diet and prevention (dietitian, nurse)
--prevention information beyond 'smoking causes cancer'
--prevention education skills (dietitian, community lay educators)

4.11 Cultural and Language Barriers

Some participants raised language barriers (South West Health & Capital Health) and cultural barriers (Capital Health) as factors requiring increased awareness and consideration in patient assessment. Descriptive data was scant in this area.

5.0 LEARNING PREFERENCES & BARRIERS TO CONTINUING EDUCATION

Overview of Key Findings:

Discussions generally supported continuing education (CE) programs that are consistent with adult education principles, providing opportunity to learn relevant, useful information in an environment compatible with their learning styles and facilitating sufficient interaction to meet both their professional networking and learning needs.

Participants across disciplines reported significant contextual resource barriers to participating in continuing education. These included: lack of coverage, loss of income for fee-for service reimbursed physicians, lack of paid educational leave for salaried professionals, and lack of time.

- In the context of human resource and time limitations, there was a strong preference expressed for short sessions, delivered locally and/or regionally. Videotaping, and multiple continuing education delivery mechanisms may be required to reach participants given the resource and time constraints.

- Case study approaches received positive appraisal from some physicians, nurses and pharmacists who also identified its positive impacts on multidisciplinary team work. First hand reports indicated that even in a simple form (such as a case based scenario accompanying a patient discharge summary), case study materials facilitated a multidisciplinary approach to care.

- There was no clear preference regarding continuing education formats or delivery mechanisms. Specific formats for continuing education were explored differentially among groups. Telehealth and the Internet received mixed reviews. Telehealth, while improving access was perceived to have at least two limitations: videotaping restrictions and interaction. Some participants viewed the Internet as a means to more easily access protocols and guidelines.

- There was some recognition that local expertise and resources were underused with respect to continuing education. The underlying themes of human resource and time limitations suggest that current capacity to engage local resources in delivering intensive continuing education efforts may be limited. This would need to be explored further at a district or regional level.

- Interdisciplinary continuing education appeared to be endorsed in principle by some participants, but its acceptability would depend to some extent on the topic. Palliative care was viewed positively and emerged most clearly as a suitable topic for interdisciplinary education. This implies it may be an appropriate model to examine if planning education on other topics.

Key findings are further described below.

5.1 Learning Preferences and Continuing Education Formats

Nine of the ten groups were asked to comment on their preferred learning methods and continuing education formats. Methods or formats were differentially explored across groups and some groups discussed particular methods and formats more than others. Internet use appeared to be probed more systematically. Despite the limitations, the information obtained contributes to an understanding of how various methods and formats fit into the continuing education lives of the participants, in the context of significant resource barriers to continuing education.

5.1.1 Short, Local Sessions

> "I think it would have to be in short episodes, from a time management point of view." [physician]
>
> "I mean, day long things, it's just too hard to get to them." [another physician]

Many participants across professional groups indicated preferences for short sessions that are held locally. This preference was strongly articulated among physicians, but also expressed by other health care providers. While the data presents some factors to consider in determining the best time, duration, and locations for CE, it also suggests further assessment within districts is needed to develop the most acceptable programming.

The demand for short episodes, delivered locally appears related to:

- problems providing coverage of patient care which constrain the participants' ability to attend CE,
- the amount of time available to attend CE, and
- compensation issues, such as loss of income for fee for service providers and paid leave for salaried professionals.

5.1.2 Case Study Methods

Two groups expressed positive attitudes toward case study approaches, each emphasizing their value in a multidisciplinary approach to patient care. The two discussions excerpted below were remarkable in that expressions of general agreement were spontaneously elicited from other group members, suggesting strong support, at least among these participants, for case study methods. Immediate applicability to patient care using a team approach appears to be a key element.

> From one district: "[Physician:]…you might know a lot about what drugs the patients tolerate best and what side effects they really do have, right? And that's very good information for me because I might write the right script next time. And yet, you might know from me how much pain those patients really have and what they're going to need.
>
> [Pharmacist:] So in those cases it's probably best if it's sort-of-a case study approach then. […]
>
> [Another physician:] That's actually an excellent idea if you were doing a multi-discipline approach, is have case studies."

In another district, participants commented positively on how they worked together more effectively as the result of the health care team using a case-based scenario provided with a patient's discharge summary. This example highlights the value of informal, but immediately applicable learning opportunities supported with highly relevant case study materials.

> "[Nurse:] [speaking] of successful case studies…that one that we had, […] that worked very well in terms of palliative care, follow-up, the home care, the whole team really…the family.
>
> [Physician]: We worked together.
>
> [Nurse]: It was magnificent.
>
> [Physician]: We had a palliative patient that came back with IWK with a discharge summary and a case-based scenario attached to it for information for the caregivers. And I thought, 'everybody should read this', so we made it mandatory that everybody who took care of the patient had to read it and initial it. But it worked, and we all learned from it and then we took care of the patient and it seemed to have worked very well.
>
> [Nurse]: It really worked out.
>
> [Pharmacist]: Yeah, to take a successful case like that and talk about it and see how it can be….
>
> [Physician]: And everybody added extra value because they started from the same point and then they added extra value to the patient's care; it was excellent."

The significance of the case study method rests also with its adaptability to a variety of delivery mechanisms and formats, including print resources, inservices, study groups, the Internet, Telehealth and workshops. This is important since no single format or method received universal support among participants, consistent with the view that different people with different learning styles will prefer different formats.

5.1.3 Internet

Eight of the ten groups contained discussion pertaining to the use of the Internet for web based learning. The Internet as a continuing education program delivery method evoked a mixed reaction, with convenience and level of interaction appearing as some of the factors influencing its acceptability. Its potential use to disseminate standards of care and protocols was evident, although some indicated print resources may be required because of access barriers. Several participants also wanted to be able to direct patients to reliable web sites.

- Reliable Web-based professional information resources

  Several participants in different disciplines made reference to using the web to find information related to cancer care. Discussions did not explore this area, so little is known about what types of information they were seeking or the kinds of sites different professional groups accessed. A few participants described difficulty sifting through vast amounts of information available on the Internet.

- Continuing education programs on the Internet

  Mixed reports: While there was not extensive discussion concerning the use of the Internet for structured educational programs, some information was obtained in three groups, mainly from physicians. Reaction to the Internet for this use was mixed, although it clearly appealed to some participants. The Internet received some support as a suitable educational medium for some (unspecified) program topics.

  > "The Dal CME on the Internet, the courses they have, I mean, I like doing them. [...] the nice part is you just do from your home whenever. You type in your password and you do it at 11 o'clock at night or 7 in the morning, or whenever you have a free half hour. I'm doing one on [****] right now.

  Convenience and interaction: Convenience is one factor favouring Internet use by some physicians, as the preceding comment clearly indicates. The degree of interaction is a factor for others, who indicated the Internet was not personal or interactive enough for them. This disadvantage can be overcome through real-time programs, as one physician enthusiastically described.

- Accessing Standards of Care

  The Internet was viewed by some as an acceptable delivery mechanism, for credible, up-to-date, readily applicable information on standards of care and pharmacotherapeutic protocols. This was raised in four groups.

  > "Well, that's what I said earlier, we should have a published set of standards of care. Personally I would like to see it Internet-based and, by that I mean a Nova Scotia standard. It would be nice to see what the other standards are, but I think I need to know what the accepted treatment is here and now, you know, that's what I need to know. I mean, I don't care what it is in California" (A physician addressing another physician participant).

Ease of access and use is highly relevant in the context of system-wide time constraints faced by health care providers across disciplines.

> "I'd like to see Internet resources that are readily accessible. I'm kind of a Luddite, and when I get on that thing I don't know where I'm going and it's hard for me to find things. But I see down the road that probably a lot more people are going to be on computers and that kind of knowledge is there …When we are motivating people to learn, we have to tailor…we have to bring it to them because gone are the days when people are going to go out of their way to do things. So….what's the leading edge? What works? You now, we hear today it's not so much what you do, but is it proven that what you do helps?" (nurse and cancer volunteer)

An attractive feature of Internet use is being able to access and download current information at anytime. A few physicians and a pharmacist discussed the use of palm pilots in this regard:

> "I just had this brainstorm…we're all getting palm pilots, right?...But as you update them, I mean when we do cur little 'hot synch' thing, we would always have up-to-date information literally at our fingertips…
>
> I think they are great…I find it so much easier to pull out a palm pilot in front of a patient than to look them up in the CPS…" (two physicians discussing)

- List serve: A *Cancer Care Nova Scotia* list serve was suggested by one physician participant.

- Internet access issues: The following issues concerning access were raised in four groups:

  --High speed access is not available in some locations e.g. Guysborough Antigonish Strait Health Authority.
  --Lack of access on hospital wards necessitates the use of personal home computers (raised by non physician participants).
  --Licensing costs are prohibitive for specific programs of interest to participants (e.g. a program offered by the Princess Margaret Hospital) would require provincial implementation, for example by *Cancer Care Nova Scotia*.
  --Paper copies and print resources will still be required since not everyone has worksite access or will use web based resources; and print resources (e.g. bulletins or updates) can be looked up easily in a binder format.

- Web-based patient resources

  In five groups, urban and rural, participants raised Internet use by cancer patients, resulting in "reams" of sometimes conflicting and overwhelming information. One physician commented on the need for increasing critical appraisal skills in order to better interpret information patients are obtaining from the web. Several participants across disciplines agreed that they wanted to able to direct patients to reliable cancer information sources, including web sites.

5.1.4 Telehealth

Information on Telehealth emerged in eight groups. Reaction was mixed, and ranged from positive to negative. Some nurse participants from Annapolis Valley Health and Cumberland Health Authority were very enthusiastic about its role in continuing education:

> "And I tell you , we access Telehealth a lot from our facility. Anything and everything that's on at the hospital here that we can access, through Telehealth, we do." (Long term care nurse)
>
> "That's our number one way of getting our educational needs out, it works really well." (VON nurse)

A manager from another group (post group) commented that Telehealth had not been useful, describing it as a "nightmare to set up" and too time-consuming. One physician from a different group commented on poor technical quality, likening it to a "poor recording," adding,

> "It's very inflexible, it's a very great disappointment really and it costs a fortune."

- It's Improved Access: Comments across several districts indicated that Telehealth had increased accessibility to educational opportunities. Increased accessibility is important in a context of geographical, time, funding and human resource barriers. Telehealth is being investigated in one district to provide palliative care education, as an alternative to staff conducting sessions in other facilities. One participant summarized a Telehealth discussion, "But at least they all [hospitals] have Telehealth, it's not always good, but at least there's an option available." (Cumberland Health Authority participant)

- Its Limitations: Telehealth was not systematically explored as a continuing education medium, however, some participants identified the following limitations.

  Timing, Convenience & Videotaping:

  Attending a Telehealth broadcast can be "a real struggle", in the words of one physician, as busy practitioners and other health care providers experience time conflicts with established sessions, such as the oncology rounds.

  > "It's frustrating for the people broadcasting , but it's also frustrating for us because there's no good time to do it." (health care manager).

  Videotaping Telehealth sessions to overcome access barriers was mentioned often by nurses. Restrictions to videotaping limit access. Some sessions of interest could not be videotaped because presenters denied permission. In the Guysborough Antigonish Strait Health Authority group, the requirement that someone attend a session at the site in order to videotape was expressed as a barrier, given the geographical distances involved. It was noted in this group that rural physicians were unlikely to devote a half a day, including travel time, to attend a daytime Telehealth session. Central videotaping was suggested as a means to make videotaped sessions more readily available.

- Facilitation and Interaction:

  Participants in at least four groups clearly preferred more interaction in their learning environments than Telehealth might offer. However, discussion among some physicians and nurses indicated that if conferencing was skillfully facilitated, with small enough groups, participants had more satisfying experiences and felt included.

- Promotion:

  --Telehealth events not promoted well in one district. Physicians described no communication about forthcoming sessions, noting word traveled "via the grapevine."
  --Notification by email was recommended.
  --It was suggested in the same district that community based nurses and pharmacists be included in Telehealth coordinators' promotional efforts.

5.1.5 Other Continuing Education Formats

- Cancer Care Newsletter:

  In two groups, physicians and nurses suggested that one page in each Cancer Care newsletter issue be devoted to a CE topic (such as the common cancers, treatment, comfort measures). Brief, relevant information that could be readily applied to patient care was stressed.

- "Hands-On" Experiences

  Useful, hands-on experience for further skill development was requested for nurses in specialized areas, such as chemotherapy (experience in a larger centre for IV's,) and cervical cancer screening (additional practicum). Similarly, other nurses expressed interest in having experts visit to refresh skills on infrequently encountered procedures, such as portacaths.

- Lectures

  Short lectures received some support, particularly when arranged within existing regular continuing education time slots (e.g. 8 am Wednesday morning CME in Pictou County).

- Conferences & Workshops

  As the time and resource barriers to continuing education indicate, conferences and workshops, while "great," are difficult to attend. Shorter, half day workshops may be more acceptable to some groups, such as nurses. It was clearly stated by some physicians that fee for service providers will not attend workshops in normal working hours.

5.2 Learning Environment

- Learning in a social setting: Participants from different disciplines in one group agreed that the model used effectively by pharmaceutical companies was appealing to them. Comments in other groups lent support to their assessment of its attractive features: a continuing education component of short duration delivered in conjunction with a meal ('you have to eat anyway') that allowed participants an opportunity to network with others in a relaxed setting away from the work site.

- While participants did not otherwise comment directly on conducive learning environments, the data raises some questions about on-site settings (particularly for nurses) if systemic funding and human resource issues are not addressed. Even CE sessions of short duration held on the unit require coverage, however minimal. Staff sometimes are not totally relieved of their responsibilities to concentrate on learning (e.g. There were reports of running in and out to answer call bells, feeling guilty became someone else is picking up the attendee's work load, fearing being pressed into work while attending on an official day off.) Similarly, while local sessions increase the chance on-call physicians might be able to attend at least some portion, their focus on learning is by no means assured as they receive pages.

5.3 Promotion of Continuing Education Events

Five groups provided information on promotion of CE events, suggesting that events need to be adequately promoted with enough advance notice (minimum 1-2 months suggested) so coverage may be arranged. E-mail, posted noticed and items in publications were suggested. In Cumberland Health Authority, Pictou County Health & Guysborough Antigonish Strait Health Authority broadening promotion to more professionals outside of the hospital setting was advocated.

5.4 Community Resources for Continuing Education

Seven groups (outside Capital Health) explored the availability of local continuing education resources.

- Local resources and expertise: Comments suggested several participants gained an increased positive awareness about local expertise and resources from attending the focus group meeting.

> "Well, just look at the resources around this table right now." [long term care nurse]
>
> "I don't think we're using our resources that are actually here, 'cause I don't think we actually know what's here. Because, you know, I could probably access information from you guys that would help me in my day to day practice. I'm going to do that." [VON nurse]

- The under use of local continuing education resources was noted in some groups. Several participants reported positive experiences using local palliative care resources effectively in educational efforts, or identified it as a potential resource. Pharmacists also were recognized as somewhat underused local resources.

In two groups, participants spoke of the potential for a series of sessions using local and outside expertise from *Cancer Care Nova Scotia* (e.g. 'lunch & learn' in South West Health; a series of three Saturday sessions per year based on top identified needs in Annapolis Valley Health). Local leadership was suggested as needed to implement this type of activity. A patient navigator in another group suggested navigators with their access to resources might play a role in bringing the community together around some issues, such as caring for lines and febrile neutropenia.

- Capacity to participate: Participants were not asked to assess the capacity of locally identified resources to contribute to CE in the context of funding and staff shortages. However, the theme of resource limitations that pervaded many discussions raise questions about local capacity to increase CE involvement. In one district, growing program demands without staffing increases have altered educational outreach efforts by palliative care.

5.5 Barriers to Continuing Education

Participants identified human resource, time and compensation barriers that need to be considered in planning continuing education activities.

5.5.1 Coverage

Human resource constraints lead to difficulties providing adequate patient care coverage, thus constraining health care professionals' ability to attend CE. Coverage is an identified barrier, raised in most groups given the opportunity, and is a problem faced by several different professionals.

- Physicians: Participants from South Shore Health, South West Health and Annapolis Valley Health reported there are not enough specialists and/or general practice physicians to relieve those who might wish to attend CE outside the community, making continuing education in the local setting a necessity.

> "And there's another big issue which is, for physicians anyway, everything is governed by the call schedule. And when you're on call, by and large, you can't leave town, [...] the only way you can get out of town is often by switching call with somebody else, and people don't like doing that, or leaving the place uncovered which is subject to a great deal of argument right now. Therefore, for physicians anyway, basically something has to take place here because then you can at least come if you are on call."

- Nurses: Nurses reported there were insufficient nurses available to relieve staff so they could attend programs. This was described specifically in Capital Health, with supporting evidence from other districts. Short staffing has resulted in demands to work additional hours, and the need to protect personal time off. Sometimes staff are refusing to back-fill so co-workers can attend in-services. Nurses have felt pressured to stay and work when they attend in-services on days off.

> "Even I hate to come in for an in-service on my day off, because they'll grab me to work! I mean, how many times, in the middle of an in-service, has someone

> come in, and you're thinking 'oh no, I'd better get home' or they're gonna make me stay."
>
> "There's no staff to replace you."

One nurse manager observed that staffing levels do not permit nurses to critically read print resources and obtain information they might apply.

- Other Health Care Professionals: Pharmacy, dietetics and physiotherapy expressed similar concerns with respect to coverage, with no one to relieve them or having call schedules similar to those of physicians that made time away for CE difficult to manage.

> "It's difficult to get to anything educational because a lot of times there isn't anyone to relieve you, if you're the only person…there's a lot of us who are like that, so that you don't get to conferences or any way of educating because you can't leave your department to do it. For me, that's the biggest problem."

5.5.2 Time Constraints

- The amount of time professionals can give to CE is limited. Short sessions are preferable in this context, especially when coverage is problematic. Busy clinics, full schedules, staff shortages, other competing demands (meetings, other CE requirements) are the reality. Time constraints are also related to compensation issues and to travel distances, as discussed in sections below.

- Time of day: Physicians and some hospital and community based pharmacists expressed a desire to have CE outside of normal working hours, either earlier in the morning or late in the day, and not on a week day for a full day session. Surgeons find it difficult to attend morning sessions. In one district, hospital nurses indicated the afternoon rest period was the best time of day for short CE, while late morning was a better time for long term care staff and evenings more convenient for home care nurses.

- Programs might need to be repeated and/or videotaped to reach the most people. Nurses in community and long term care settings remarked on this. Making use of CE times already established in some locations also offers the potential to reach more participants (e.g. Pictou County physicians meet regularly on a Wednesday a.m.)

- Travel Time & Location: Several participants in most groups indicated a preference for continuing education delivered within the district to increase accessibility. There was no preference expressed for Halifax, with time and cost cited as an influencing factor.

  There were appeals to consider holding continuing education events in outlying areas within the districts (including Capital district). Drives over an hour may not be acceptable. Telehealth was mentioned as an alternative in Cumberland Health Authority.

Data suggests locally-defined balances must be struck with respect to acceptable travel times and continuing education. People in some districts (e.g. Cumberland Health Authority & Guysborough Antigonish Strait Health Authority) may not be willing to travel longer distances to reach central locations within the district for sessions that may be perceived as too short. Yet in South West Health, travel to locations such as Liverpool or Digby may be an acceptable compromise, as one physician described.

5.5.3 Funding and Compensation Barriers

Across several professional groups, barriers exist related to compensation for time to attend CE. As summarized by one physician,

> "…certain people are working on income that's derived from fee for service, and so, in order to do the learning experience, you lose the opportunity to operate on a fee for service basis; and some people are salaried and not given the opportunity to get paid educational leave, right? It's the whole thing of who reimburses the learner."

- Loss of income to attend CE is an identified barrier for fee-for-service physicians. Continuing education and income loss must be weighed with other priorities such as compulsory CE, family and vacation time, hence the desire for sessions outside the normal work day.

> "You can't justify losing a day's pay"
>
> "[CE sessions for] doctors have to be either first thing in the morning or after hours, I mean, you know, you're dealing with a bunch of people who are fee for service. If you take them out of their office for 2 hours in the middle of the day, that's 2 hours they're not getting paid, it's bottom line."
>
> A community-based specialist described a need for sabbaticals to enable physicians to have learning experiences beyond professional reading and conferences: "even a week down there [Dickson Centre], you know, but there's no funding."

- Lack of paid education leave to attend workshops and conferences is a funding-related barrier for nurses and other salaried professionals. Special CE events aside, nurses in Capital Health also reported coming in on their own time to attend routine in-services, underlining the critical nature of the funding and staffing problems. Even short programs will require coverage. It was also pointed out that salaried professionals even though they may do CE on their own time or expense are not able to claim income tax deductions. The following comments from several districts and different professionals highlight the problem:

> "They have to realize that some of the money has to go to pay people to take some of this education. Some will be voluntary, but the very basic things, the pharmacology and the things that we really, really have to know." [oncology nurse]

> "I work as part of the education committee for the [****] and people are just not getting the time off, or the money to go out to something." [social worker]
>
> "The problem with this area is time and staffing. Our nurses can't get even get time off to attend conferences that are local. There's just... money is so tight and resources, it's people resources...it's tough. [nurse]
>
> "Sometimes there isn't someone to replace you so you can go, and the funding is a problem as well. You don't....as much as you say, 'well, I'd like to go to this, I don't mind paying for it, I don't mind going on my day off'. it's also nice to have them say, 'we're going to pay for your registration and we're going to pay you to go, you know, and you have can have another day off instead.' [pharmacist]

5.6 Interdisciplinary Continuing Education

Eight of the ten groups had some discussion about various aspects of interdisciplinary education, and one participant from a non discussing group provided written comments after the session. Interdisciplinary continuing education appeared to be endorsed in principle by some participants, but its acceptability would depend to some extent on the topic. Palliative care was viewed positively and emerged most clearly as a suitable topic for interdisciplinary education. Other topics were suggested for interdisciplinary education, but there was insufficient data to assess their appeal. They included pain and symptom management, dealing with the patient holistically or as an individual, ethical issues, and community resources. Groups under explored problems that might exist concerning bringing together the different disciplines.

5.6.1 Past Experience

Participants in several groups reported positive experiences with interdisciplinary education or meetings. Interdisciplinary palliative care education was very positively assessed in four groups (South West Health, Colchester East Hants Health Authority, Cumberland Health Authority & Pictou County Health) as was the interdisciplinary model used in the RN Pap –Community Educator pilot program (Cape Breton District Health Authority).

> "I think one of the things that made us successful [palliative care in Colchester East Hants Health Authority] was the fact we went away for education sessions together. So you were together as a team" (nurse)
>
> "Remember way back, a couple of decades ago, when we did palliative care in a more in-depth way and we did have community leaders, pharmacy [...] mental health, physicians, nurses who talked about best practice at the time. And we educated each other and it was excellent and it was very collaborative [general agreement in group] And then you became part of a team and would continue to work together because you could learn together. And then you identify your needs within the group and you think 'oh, somebody should give us some help with that,' and may one person who's well connected... (physician)
>
> "We have utilized whoever necessary to ensure the nurses and educators have the information and training they need. This has made for rich learning

> experiences. At the same time we have encouraged the use of their own expertise by putting them in educational /facilitative roles as well." (pilot program program representative)

5.6.2 Attitudes and Opinions

The concept of interdisciplinary education appeared to be endorsed at least in principle across disciplines and in most districts, especially with reference to team building and functioning and the multi-faceted nature of cancer care. However, some reservations and cautions were expressed by participants from different disciplines.

"It depends on the topic". There was general agreement in one group, with supporting comments made in 5 other groups that interdisciplinary education could not be used for everything. In essence, it depends on the topics. Individual professions had specific information and skill development needs that were of specific interest to them. There were concerns that interdisciplinary education could be too "broad" or "watered down" to be useful or appealing. Some expressed there are still specifics that professional groups need to know that are best handled within their own discipline. There was a call from one group for integration of information, so that across and within disciplines, patients were being provided with consistent information.

What was of broader interest though, was knowledge about what other professionals knew, and how their knowledge and skills could contribute to patient care. This was expressed across several disciplines, often by physicians.

> "I don't think everything should be [interdisciplinary] because our professional interests haven't left our minds from years ago when we chose this specific field. So I don't think that I need to know all the specifics of social work. I need to know what I can get from a social worker". (physician)

5.6.3 Making Interdisciplinary CE Work

This question was superficially covered.

Overall, the data suggests there are elements in the palliative care area conducive to interdisciplinary education, such as a clear patient care focus, a recognized need for shared expertise and an opportunity for team building incorporated into the educational processes.

However, in two districts, a few comments suggested that there are difficulties with respect to bringing physicians and nurses together for interdisciplinary programming. While the issue of difficulties was raised, it was not explored.

5.6.4 Most Appropriate Topics

Six groups were asked to comment on the most appropriate topics, and not all groups dealt directly with the question.

> *Palliative care.* One topic, palliative care, was clearly supported in four groups as an appropriate area for interdisciplinary education. Palliative care may be an appropriate

model to examine if planning education on other topics. The following dialogue illustrates:

"[Physician]: Yeah, palliative care goes well in an interdisciplinary format.

[Pharmacist]: That's where you really are in the nuts and bolts and you can share the different expertises."

[Physician]: That's right. It's certainly a better chance of seamless care if you get a multi-disciplinary or interdisciplinary group."

Other topics with interdisciplinary appeal:

These topics were raised and supported in a few groups, but there was unsufficient data to fully assess their appeal:
--pain and symptom management (not specified as palliative care)
--"a holistic picture of the patient with cancer" or "dealing with the patient as an individual", described as communicating with the patient, dealing with how the patient is reacting, and cancer process issues (distinguished from cancer treatment issues).

Topics suggested once:
--ethical issues (unspecified)
--available community supports and how to access them.

6.0 WORKING WITH THE CANCER TREATMENT CENTRE

Overview:

Although the main purpose of the focus groups was to examine cancer educational needs, communication, coordination and relationship issues with the cancer treatment centre were raised in most groups, and appeared to be an important theme.

It should be noted that some participants perceived poor communication and coordination as a system wide issue that also exists at the local level, and not only in the relationship with the cancer treatment centre. (Communication issues also were reported with reference to Moncton cancer care services used by some patients in Cumberland Health Authority.)

Key findings included:

- A poor flow of information from the cancer centre regarding the patient's condition and treatment, including untimely reports, was a significant issue. Impacts with respect to patient care are described in section 6.1.
- A lack of coordination, sometimes related to communication problems. This was perceived by some participants from different disciplines. The need for clearer guidelines was expressed, regarding who checks what, when and how.

- Communication and coordination problems seemed to have other intangible aspects. Perceived poor communication may contribute to a sense that the patient is "taken over" by the centre and in some cases, that district expertise is undervalued.

- There was also a perceived need among some participants for an increased awareness and understanding on the part of the cancer treatment centre with respect to district expertise, the patients' environment, available district resources and their limitations.

- A portable patient record was explored as a means to overcome communication problems, and received some support.

Aspects of the communication and coordination issues are described below in more detail.

6.1 Communication Issues

Communication issues with the cancer treatment centre were identified in all but one focus group. While different groups described various aspects of the problem, this concern was extensively and sometimes intensely expressed, sometimes with strong agreement within groups.

- Poor flow of information from the centre to physicians in the district was a predominant complaint. While there was one report from a surgeon (treating mostly breast and bowel cancer) that the communication and information flow from the Halifax cancer treatment centre has shown continuous improvement, problems are still perceived to exist in many districts. Lack of communication was described directly by some specialists and family physicians, and was observed by nurses, pharmacists, social workers, managers and family members of cancer patients.

  > " Halifax is this great black hole that a patient disappears into and we never see them again sometime, or if we see them, usually when I see them is when they're in distress. There's no feedback, or minimal feedback, it's late…." (specialist)

  As one nurse participant remarked,

  > "it becomes a specialist's world in terms of care of the oncologists for the patients and the family doctor is often left 'out of the loop.' "

- Untimely reports: Physicians in several groups reported not receiving timely reports and feedback about the patient's condition or treatment. (Specific reports of 6-8 weeks or 'months'). Reports of poor communication concerned both the Halifax and Cape Breton centres (radiation oncology specifically mentioned re: Cape Breton).

- Interaction with the IWK compared more favourably, volunteered physician and pharmacist participants in three groups. It was even termed "excellent" by one participant. An example of supportive communication from the IWK is the case-based scenario that accompanied a palliative care patient's discharged summary, (described more fully in section 5.1.2 Case Study Methods).

- Routine & special information needs: While occasionally receiving phone calls "if something came up," physicians sometimes had to contact the centre to find out information of a less urgent nature after patients' appointments because it was needed in their practice situation. Both an overall awareness of usual treatment and the special aspects of individual patient's cases are important information needs as this comment highlights:

  > "In the rural communities, the family physician is known, a lot of times, for a very long time, and he's the one, or she's the one, [patients are] going to go and talk to, and they need to know that information. So they need to be, you know, educated as to what's available, what their routine care is, and then, as well what's special in this particular case." (physician)

- Patient Care Impacts: The following impacts were reported. Sometimes district physicians do not have up-to-date knowledge of the patient's condition and treatment, yet they may still have to provide care for patients with urgent complications or for other medical problems with these information gaps. Patients are sometimes returned to family physicians for end of life care, after periods of non involvement and no information. Providers reported having to contact the treatment centre and/or rely on information provided by the patient, who may not always understand. Health care providers' ability to answer patients' questions is hampered.

  > "As a local specialist, I'm the one that the family doctor calls when they see the patient's in trouble on Friday night, and I don't know what's happening with the patient. So, there's a real lack of coordination, a lack of intercourse between Halifax and us." (OB/GYN specialist)

  > "When he'd be home from treatment and need to be seen here, I carried a binder around with copies of all his charts because it was the only way the doctors at home knew what was going on." (health care professional participant describing personal experience with a cancer patient family member)

- Other Impacts: Some physicians described how their lack of up-to-date knowledge of the patient's condition and treatment undermines the patient's confidence in their medical care. Some physicians also feel excluded and undervalued, seeking to be part of a team, but yet not adequately equipped with timely knowledge to do so.

  > "I just don't feel like there's a value placed by Halifax on anything outside of there, so there is very little communication back." (specialist)

- Technological Issues: An issue raised in Capital Health was the incompatibility between the Cancer Centre and QEII data bases, hindering easy access to patient information.

- A directory, including fax numbers of cancer treatment centre oncologists and resources was one recommendation to improve communication with positive implications for team functioning.

  > "I'd like something simple, actually. A telephone directory of people involved with it. We've been asking for years, we haven't got one yet. One of my patients

> brought me in a little card from an oncologist, with a fax number on it—I don't have it." (physician)
>
> Yeah, working as a team always works better when you have a number to give somebody a call." (another physician)

6.2 Coordination Issues

These issues were also apparent in data, and appeared to have particular significance with respect to follow-up of patients at the district level. Knowledge of team member roles and responsibilities, available resources and communication among providers are also factors in better coordination and team work at all levels in cancer care. Additional perspectives on the issue can be found in section 4.4 Interdisciplinary Teamwork).

6.2.1 Lack of Coordination

Lack of coordination in cancer care was a problem observed by several participants from different disciplines, with a few groups dealing with this issue in more depth. One specialist termed it a "big" problem. Lack of coordination results in delays, duplication, and "falling through the cracks" with respect to follow-up. Some factors identified as contributing to coordination problems: uncertainty about preferred diagnostic and follow-up routes, the involvement of several physicians (family physician, surgeon, oncologist, radiation oncologist) and poor communication.

"Road maps" are needed at the diagnostic and follow-up stages, as one physician expressed, defining who checks what, when and how.

6.2.2 Follow-up at the District Level

- Some community based specialists emphasized their willingness to be part of the treatment and follow-up team, with perceived benefits to patients (reduced travel costs and inconvenience) and the system (freeing oncologists to handle more difficult cases).

  > "...perhaps we could do more here, perhaps there could be fewer trips to Halifax, perhaps there could be more information transfer rather than the patient having to make that trip." (community-based specialist)

- Barriers:

  Some physicians also indicated it was difficult to provide this care because of untimely communication, insufficient communication on protocols, and sometimes, a perceived under-valuing by the cancer centre of the skills and expertise available at the community level which can "rob" community specialists of their credibility with patients.

  Specialists in three groups appeared to perceive that attitudinal barriers to receiving local follow-up care are somehow created when the patient enters the cancer treatment centre. As one physician said, "Something gets lost in the transition." There was a sense that the patient is "taken over" by Halifax. Others related that patients may be directly told they must receive follow-up at the centre or they may feel local care is not of the same quality. Patients may believe, that "really our cancer doctor is in Halifax," despite the community based specialist's involvement in their cancer care. A surgeon has observed that patients are disinclined to refuse follow-up visits in Halifax, even though they would prefer more local follow-up for fear the "door will be closed" to the cancer centre.

6.2.3 Other Coordination Problems

- Lack of clear guidelines and miscommunication about information needed for treatment centre consultations may lead to unnecessary delay. While not extensively reported, it was highlighted by one group's example:

  > "If they had just called the nursing station we could have faxed the reports. But no, they sent that person back by ambulance. There was an expectation that we should have known what should have been sent. And that was really frustrating because there was communication with a consult nurse, we said 'do we need to send anything?', 'no', But when we got to the radiation oncologist, he said, 'no, no, we're missing this, this, and this' and back the client came." (palliative care consult nurse)

- Pharmacy issues also emerged, with reports of patients discharged to their home communities (often on a Friday), with oncology specific prescriptions not normally stocked in community pharmacies. This problem could be remedied by better communication. In comparison, the IWK reportedly has communicated with local pharmacies to coordinate patients' special prescription needs.

6.3 Awareness of District Conditions

Participants in three groups raised the need for a better understanding by cancer centre personnel of regional conditions, resources and patient circumstances. This could assist in making follow up more accessible at the district level and smoother coordination of care when patients are returned to the district.

- One surgeon commented while staff oncologists have a better understanding of local medical resources, many residents do not and may misinform patients they need to return to the centre for all their care. Other specialists (Ob/Gyn and internal medicine) commented on the perceived undervaluing of district expertise.
- Some other health care providers (nursing and lab tech) described instances where the centre discharged patients home expecting a certain service or ability that was not present or developed (e.g. pain pumps, lines) in the district.
- It was perceived by some that patients' circumstances were not always well understood by cancer centre staff. Some examples: early appointment times did not consider travel distances and insisting that all gynecological malignancies requiring chemotherapy be treated at the centre, without regard to patient inconvenience.

6.4 Portable Patient Record

Health care providers in the districts are concerned about their lack of up-to-date information on the patient's condition, laboratory and diagnostic reports, and therapeutic interventions. Some feel they do not know what is going on with the patient. While some patients and families assemble this information on their own, often patients are stressed, ill, and do not know or understand important information that could assist professionals in providing their care.

Discussion about a portable patient record was stimulated by the facilitator in 5 of the 6 groups that commented on the concept. Five groups expressed support for a record in the patient's possession that could be viewed and used by team members. There appear to be some ad hoc attempts to provide patients with summary copies of chemotherapy related information that can be presented in urgent situations. There were positive reports concerning the use of a palliative care patient record maintained in the home and used by various team members. One Obs/Gyn specialist cited, as an effective model, the universal summarized prenatal record carried by patients.

- Readily available information is important when cancer patients experience complications and are seen for urgent or emergency care as often patients are stressed, and do not know or understand important information. Other health team members, such as community pharmacists also indicated they would like access to summarized information in providing their services. The following advantages of a record in the patient's possession were perceived: reducing repeated histories and assessments, increasing the patient's ability to self advocate, and importantly, facilitating communication of the patient's condition and team work.

  Dialogue re: common chart owned by the patient:

  > " I mean patients do have to advocate for themselves nowadays, regardless. But you know, to have everything in one place would make it a lot easier. (social worker)
  >
  > It's also for them to process the information. (nurse)
  >
  > It would be easier for physicians, too. Because the communication back from [the centre] is so slow. The patients will come back six to eight weeks after their visit in Halifax and I have no report, so I have to depend on what the patient tells me… (physician)"

  From another district:

  > "I certainly find that our palliative care chart in the home…we ask our patient to take those with them when they go for any appointments. But what I find useful is, you know, if I go in today and see a patient I can read back the last couple days what the VON nurse has written, because they'll write a note each time, and I'll write a note and it just carries on like that. And I find it's quite useful." (physician)

- Potential pitfalls: While recognizing a need for better access and communication of patient information, some participants also pointed out potential problems. These included: double-charting, patient compliance, difficulty maintaining comprehensive complex summary records, or providing copies of reports to patients for their records when they are already slow in dissemination. The merits and ethical issues posed by an electronic chart were raised in one Capital Health group.

7.0 OTHER SYSTEMIC ISSUES AFFECTING CANCER CARE IN THE DISTRICTS

- The inter-related systemic contextual issues of funding, human resource and time limitations were an underlying theme in the focus group discussions overall. This theme emerged, despite restructuring of the group process to refocus participants' attention on the continuing education questions. Different groups dealt with different aspects, and had different opportunities to explore issues. Participants described how human resource and time constraints can pose barriers to treating and caring for patients, affect the implementation of a multidisciplinary approach, and reduce opportunity to participate in continuing education.

- The financial burden of cancer care to patients was of concern in several groups. Inadequate financial coverage for medications was emphasized, for patients at home and those with incomes above the $15,720 cut off.

- Access problems were described, with some support evident for chemotherapy and follow-up services delivered closer to home in order to relieve patient burden.

- Some specific gaps in palliative care services and resources were raised in several groups including resource and policy barriers to delivering palliative care in long-term care.

The following sections further illuminate participants' perceptions of these constraints and their impacts on patient care.

7.1 Human Resource Limitations & Time Constraints

> "…there are too few of us, in every single discipline, trying to do too much." (physician)

Data indicated some of the ways cancer care capacity may be affected by a lack of human resources:

- Time constraints are exacerbated as professionals attempt to meet the ever present and immediate demands of patient care in situations with staff shortages. One specialist described spending large amounts of time are spent dealing with pages and ICU situations which would be handled by interns in teaching hospital settings. As a result, the specialist was prevented from doing what he/she "should be doing".

  > "I'm interested in managing them [patients with some types of cancer], and treating them and deciding the chemo and so on. There are significant barriers to what I can do, […] the main barrier being time." (physician)

- Implementation of a multidisciplinary approach can be affected by limited human resources, both in terms people available to provide care and in the time available to offer "significant input" into the approach (as one physician remarked). In a few districts, the ideal notion of a multidisciplinary team was challenged in the face of insufficient human resources. In one group, participants noted there might not even be a doctor, a nurse or a pharmacist available.

> "You now for [****] years I've done a lot of palliative care in people's home and I was 'it'. And I'm still it most of the time. And if we're talking about teams... I'd like teams to be a bit more distributed than just in the urban centres." (physician)

- Human resource limitations constrain the capacity to participate in continuing education, as discussed in section 5.5 Continuing Education Barriers. To review, staff shortages impinge on continuing education, as there are no personnel available across disciplines to provide the necessary coverage to relieve potential participants. This was reported in several districts. Heavy caseloads or workloads, and demanding call schedules reduce the amount of time professionals have to devote to educational activities.

- Some data suggested funding and human resources are not keeping pace with service demands. Palliative care for example, has experienced an increase in demand for service in at least one district, with the full potential needs unmet (seeing the "tip of the iceberg").

> "So we're constantly coming up with creative solutions on how to deal with our caseload and you reach an end where there aren't more solutions except to add more human resources and financial resources to able to assist. The same is true of chemotherapy." (nurse)

7.2 Financial Coverage & The Financial Burden of Cancer

The financial burden of cancer on patients and their families was discussed in several groups, often passionately articulated and based on first hand experience with patients. The financial burden of cancer is felt by many, including those with insurance coverage, but especially those on low income.

> "I think the biggest thing that I see in the community is it really makes a difference whether you're rich or poor...it really does. It's really difficult for people who have no money and we have to battle for it." (VON nurse)

- Lack of coverage for medication costs was a significant concern across disciplines.

> "It's a very important issue from my perspective. Because I feel guilty that I am the one that prescribes the treatment. I can look at it, but I don't know what to offer instead of that...It's tragic when the patient comes, whatever the disease, but especially this one, and say to me, 'No, I don't have money to pay.' (internist)

> "How can we help them control their pain if they can't afford the medication?" (pharmacist)

> "One of the major problems is the financial problems that families have. And one of the suggestions I would make to *Cancer Care Nova Scotia*, would be to lobby

> government, lobby the Department of Health to pay for medications, as one thing. Maybe more, but for sure medications for palliative patients." (palliative care program coordinator)

The $15,720 Pharmacare cut off was termed "ludicrous," and some participants reported many people are still falling between the cracks.

Patients are sometimes hospitalized (at higher cost to the health system) in order to receive pain and other medications they cannot afford if they are cared for at home. Medications are sometimes sought from outpatient departments for patients who cannot afford them.

Patients may face treatment choices based on cost, depending on how and where the drug is administered. For example, a hospital pharmacist noted that unless they have insurance, some patients may not benefit from orally administered 5FU (won't be given in hospital, and therefore cost not covered through the hospital).

- Other significant costs observed to contribute to patients' financial burdens:

  Nursing care costs for palliative care in the home. Patient's nursing care needs can exceed insurance company caps, or patients may not have coverage, necessitating hospitalization.

  Transportation costs.

7.3 Access Issues

Geographical barriers and accessibility: Geographical barriers affecting patient access to health care surfaced in three districts, including Capital Health which has both metro and rural populations. Travel distances and lack of transportation make some patients' accessibility to cancer care more difficult, especially when combined low income, disabilities, and/or aging.

> "Transportation is a big issue in this district, it's so big. There is no centralized mode of transportation, so I'm advocating [on patients' behalf] with agencies and services that they need the money for transportation because they're having this [procedure] done." (social worker)

Another aspect of accessibility is its potential impact on patients' treatment decisions, with some patients opting for the treatment associated with less travel, less time away from home. This dialogue from Colchester East Hants Health Authority illustrates:

> "There's a woman I know who lives in the country, so she had breast cancer and her choices become limited, because she still has to do childcare, and so although she may be offered chemotherapy or radiation or mastectomy, she has limited option in terms of her time and accessibility. (nurse)
>
> ...I have a lot of patients from my practice with breast cancer [...], but the idea of going to Halifax or staying in Halifax for radiation therapy is totally unacceptable,

> they much prefer to got for a partial mastectomy and avoid the time of radiation. And it becomes a factor for women. (physician)"

More accessible screening and follow-up at the local level was advocated in several groups, to help reduce patient inconvenience and cost. This is discussed further in the section "Working with the Cancer Treatment Centre." Chemotherapy delivered "closer to home" (e.g. in Queen's County) was supported in the South Shore Health group.

7.4 Gaps in Services and Resources

7.4.1 Palliative Care Needs

Palliative care services are in different stages of development across the province. The following information is unlikely to portray the full extent of palliative resource needs across districts. Palliative care was not systematically explored among groups, and may not have emerged in some groups because of the group composition or concentration on other issues.

--need for dedicated palliative care beds (South Shore Health & South West Health; in one case to regain what was lost in hospital bed cuts)
--expanded geographical coverage of palliative care services (e.g. a consult nurse for Hants West, Capital Health)
--expanded bereavement care identified by two existing palliative care programs (South Shore Health & Colchester East Hants Health Authority).
--insufficient home care resources to support care of people at home (no 24/7 care, shortages of home support workers)
--Long term care facility standards were mentioned as a perceived barrier to meeting residents' palliative care needs. For example, O_2 administration, pain pumps, suctioning, and IV's may require VON services or patient transfer to hospital, despite RN's presence in the facility.

7.4.2 Waits & Delays

Waits and delays were not systematically explored by district. Specific reports of long waits are listed below. Other waits and delays may exist, but were not reported.

- Specific waits & delays mentioned:
  --screening mammography in South Shore Health; diagnostic mammography in Colchester East Hants Health Authority.
  --access to GI investigations for suspected malignancy in Cape Breton District Health Authority (possibly delaying diagnoses 3-6 months).
  --Cumberland Health Authority is without a radiologist, causing delays and waits as other sites take on the load.

- Restriction on physicians' ability to order some diagnostic imaging procedures (MRI's, CAT, etc.) can delay diagnosis sometimes by months, as the patient first must wait to see a consultant, and then wait to have the procedure. Physicians in Colchester East Hants Health Authority, Cumberland Health Authority and Capital Health commented on this barrier.

7.5 Unique Issues Affecting Specific Districts

Most groups were asked to identify any other issues affecting their district (sometimes phrased as "unique issues"). Significant limitations exist with respect to interpreting the data, such as opportunity to explore particular issues and group composition. This question requires additional exploration at the district level using a more systematic approach in order to obtain a more complete understanding. Information pertaining to specific districts was incorporated into the findings, rather than presented separately.

8.0 DISTRICT CANCER CARE PROGRAM MODEL

Limitations: Findings are restricted to four groups, with three of these groups having opportunity to explore both the overall concept and the medical coordinator role. Only a few individuals across the four groups indicated some knowledge of the proposed program. The group facilitator provided much information in stimulating the discussion in the four responding groups. In subsequent groups, questions on this topic were eliminated because previous participants were generally unfamiliar with the concept.

Key Findings:

The District Cancer Care Program Model discussions revealed deep concerns about existing district resource limitations and system constraints, within the three groups with opportunity to more fully explore the topic.

Some support for the concept of district cancer care was apparent, both explicitly stated with respect to the topic and implicit in the context of other discussions concerning access to treatment (chemotherapy) and follow-up. However, funding concerns were a predominant theme, with a strong perception that the district cancer care will require new funding, that existing budgets and resources cannot accommodate the further strain anticipated with a shifting of cancer care to the districts. There was also concern that districts may be made to assume care without the necessary new resources to make it achievable and with negative impact, i.e. 'shrinking' of existing resources. Lack of support for this approach was evident.

The medical coordinator position was perceived to require new funding. Some questions were raised regarding the role, and the family physician's involvement. Separation of clinical and administrative functions were also recommended.

Key findings are elaborated below.

8.1 Funding Concerns

In the three groups responding to the proposed program, deep concern about funding was a major theme, firmly and consistently expressed. Physicians particularly engaged in discussions on the issue.

- District Cancer Care will require new funding: While there was some agreement expressed with the overall concept of providing district cancer care, some physicians, nurses, and pharmacists were adamant that existing budgets and resources could not accommodate shifting the cancer care load to the district, without new funding. Participants explained existing resources are "stretched to the limit" and there are no funds available in existing budgets to do more. The shift that has taken place already in chemotherapy, without an accompanying funding increase has negatively impacted some hospital pharmacy budgets, and planned budget cutbacks will further strain human resources if staff are reduced as a result.

> "We're really struggling in this district, that's really no secret and so there would need to be new monies..." (palliative care nurse)
>
> "I live in [****], and they're taking what few beds that we have away and taking beds away in [****] and so that shifts the load up this way. So now you're saying they want to shift more cancer patients back home, but if there's no beds and there's no supports because all the nurses have moved away, then, you know how does this all play out? (pharmacist)
>
> And this load that's supposed to be shifted up this way, we don't have the resources to handle it" (physician)
>
> "The other thing is, they are downloading, they're shifting care from [Halifax] to here, particularly with chemo. But anyone in pharmacy will tell you, it's killing their budget. So the patients who used to get certain chemo in the city are now getting it here, but now we have to pay for the drugs, which I'm sure Metro is saying 'yeah', but it's killing our pharmacy, because they didn't get increased resources to pay for these really expensive chemotherapy agents. And they get their radiation therapy in the city, but they are still not strong enough to go home, so of course we want them closer to home, but we don't have a bed to put them in. So district cancer care is a wonderful idea, but we don't have the resources to deal with it." (physician)
>
> "We're getting [chemotherapy] patients where it used to be $100 a month, is now $4000 a month, and we're told to "cut $100,000 out of your budget or you could lose 20% of your staff.' And we're not exactly...we don't have a lot of extra staff. We're running without breaks, we're putting in overtime, like, all of us." (another pharmacist)
>
> "So to talk about district cancer care until the funding issue has been addressed...I think everyone's skeptical that it's going to fly" (another physician)

- 'You have to do it, but you're not going to get the money.' The proposed program as understood by participants, does not have a clear funding structure. This appeared to heighten fears (expressed in two groups) that the government was going to expect districts to accomplish district cancer care without additional funds. Comments by individuals indicated there was some mistrust present, based on previous experience. A few voiced the perspective that policy makers and some oncologists did not appreciate the resource limitations faced by districts. It was also expressed that *Cancer Care Nova Scotia* had a role not only to encourage district cancer care, also to positively influence the government to adequately finance any new program so it is achievable. In districts already struggling with limited resources and facing the prospect of further cuts, several participants voiced they did not support implementation using an 'you have to do it, but there is no money' approach.

"But it is a new package of services…and it's going to cost money, and there is no money. And to say that you'll do it and then do it well is almost worse than not doing it at all.

I'd particularly not like to see this thing set up if it was going to take resources out, very limited resources, and shrink them even further." (two physicians)

"There is a general perception in this district, and again I'm sure it is in every other district, […] that we are at a crisis point and the entire system is about to break down. Because, everything is in the same boat. Every nurse in this place is stretched to the limit, refusing to answer the phone at home in case it is a call back on their day off. Every physician in this place is in the same boat, and people are refusing to do extra call, we're always being asked to be on this committee extra or that committee extra, 'unfortunately there's no money but we expect you to do this', and so on. And there's a general feeling […] that something is about to implode, and it's not a good [way] to tackle this, 'let's do this but there's no money for it'. (physician)

My fear is the government is going to say 'you have to do it, but you're not going to get the money." (pharmacist)

8.2 Medical Coordinator Role

- Funding for the position was a major concern in the three groups with opportunity to more fully explore the District Cancer Care Program. There was general agreement that the position required new funding. Some participants were skeptical that there were candidates available to fill the positions.
- Fragmentation of care was a concern raised in two groups, with the involvement of the family physician less clear, but still called on for weekend complications.
- Separation of a clinical/physician resource role and an administrative/coordinator role was recommended in two groups. One group suggested a non physician coordinator might provide a more holistic approach to district cancer care.

9.0 LIMITATIONS

- The qualitative findings are specific to the participants and groups involved and are not generalizable in the quantitative research sense. The findings do offer information that can assist in understanding how participants, in their contexts, view some aspects of continuing education related to cancer care and the delivery of cancer care.
- Findings may not completely portray all themes or significant factors related to a specific topic. Breadth and depth of discussions varied across groups. Possible contributing factors: large size of several groups, heterogeneous group composition, individual members' specific interests, and differing opportunities to explore topics.

- Discipline-specific perspectives were considered to the extent possible, and are not reported for all issues. Not all persons commented on every issue, and depth of discussion varied as described above.

- Participants were not systematically asked to comment on issues pertaining to specific cancer sites. Findings mentioning specific cancer sites make no inference about other sites. For example, specific information on family physicians and colon cancer screening does not infer either presence or absence of similar findings for breast cancer screening.

10.0 KEY FINDINGS

Prominent Educational Needs:

- Updated knowledge about treatment, and management of treatment side effects, pain and other symptoms. This need was strongly and extensively expressed across groups and disciplines.

- Increased knowledge about available resources, and how to access them for patient care. Every focus group highlighted knowledge gaps concerning resources for patients.

- Increased knowledge about other team members' roles, expertise and how other team members can contribute to cancer patient care. This need was expressed across disciplines, often by physicians.

- An understanding of the cancer care system and how to navigate it. This included an understanding of the patient's treatment 'road map' and their experience at the cancer centre.

- Descriptions of lower priority educational needs were also obtained, including information on screening, diagnosis, patient communication ("conveying the bad news" and discussing end of life issues), and psychosocial care.

Learning Preferences & Barriers:

- In the context of human resource and time limitations, there was a strong preference expressed for short sessions, delivered locally and/or regionally.

- Case study approaches received positive appraisal from some physicians, nurses and pharmacists who also identified its positive impacts on multidisciplinary team work.

- There was no clear preference regarding continuing education delivery mechanisms. Telehealth and the Internet received mixed reviews. Telehealth, while improving access was perceived to have at least two limitations: videotaping restrictions and interaction. Some participants viewed the Internet as a means to more easily access protocols and guidelines.

- Participants across disciplines reported significant resource barriers to participating in continuing education. These included: lack of coverage, loss of income for fee-for service reimbursed physicians, lack of paid educational leave for salaried professionals, and lack of time.

Interdisciplinary Education

- While there appeared to be support for interdisciplinary education in principle, its acceptability may depend on the topic.
- Palliative care emerged most clearly as a suitable topic for interdisciplinary education.
- Data suggested the following elements may be important aspects of palliative care interdisciplinary education: a clear patient care focus, a recognized need for shared expertise, and an opportunity for team building incorporated into the educational processes.
- Other topics, such as pain and symptom management and community resources were suggested topics for interdisciplinary education, but there was insufficient data to assess participants' reaction.

Working with the Cancer Treatment Centre

- Communication issues were identified in all but one focus group. Poor flow of information from the cancer centre regarding the patient's condition and treatment, including untimely reports. This was a significant observation made by physicians, other team members and members of patients' families. Some impacts were described, including physicians faced with treating patients with emergent or other medical problems without access to up to date information; inability to answer patients' questions, and having to rely on patients for information. Difficulties providing follow-up at the district level were reported, with respect to untimely communication, and insufficient communication on protocols.
- A lack of coordination, sometimes related to communication problems, was perceived by some participants in different disciplines. Delays, duplication or missed follow-up was described as impacts. The need for clearer guidelines was expressed, regarding who checks what, when and how.
- Communication and coordination problems have other intangible aspects. Perceived poor communication may contribute to a sense that the patient is "taken over" by the centre and in some cases, that district expertise is undervalued.
- There was also a perceived need among some participants for an increased awareness and understanding on the part of the cancer treatment centre with respect to district expertise, the patients' environment, available district resources and their limitations.
- A portable patient record was explored as a means to overcome communication problems, and received some support.

Other Systemic Issues

- The inter-related systemic contextual issues of funding, human resource and time limitations were an underlying theme in the focus group discussions overall. This theme emerged, despite restructuring of the group process to refocus participants' attention on the continuing education questions.

- The financial burden of cancer care to patients was of concern in several groups. Inadequate financial coverage for medications was emphasized.

- Access problems were described, with some support for chemotherapy and follow-up services delivered closer to home in order to relieve patient burden.

District Cancer Care Model

- Only a few individuals across the four groups responding to the question indicated some knowledge of the proposed program.

- Some support for the concept was evident, but funding concerns were a predominant theme. There was a strong perception that the model, and the medical coordinator position would require new funds.

11.0 DISCUSSION

The focus group findings, based on multidisciplinary perspectives, highlight the interrelationships between continuing education, cancer care delivery, and systemic contextual factors. These factors include resource limitations, geographical barriers, and cancer care system communication and coordination problems. These interrelationships suggest that for these participants, updated cancer cancer knowledge will be acquired and used more easily and effectively if systemic issues are addressed simultaneously. Knowledge related to treatment and resources for patients may have a synergistic potential to facilitate "seamless" patient care if system wide communication and coordination is improved. Interdisciplinary education may also play a role in this respect, particular for appropriate topics or areas that are conducive to multidisciplinary approaches. The significant resource barriers that constrain the delivery of health care in the districts will need to be considered in planning new models of cancer care delivery and continuing education initiatives.

12.0 REFERENCES

1. Morgan DL. *Planning focus groups*. Focus Group Kit vol. 2. Thousand Oaks, CA: SAGE Publications, 1998:59-63.

2. Morgan DL *Planning focus groups*. Focus Group Kit vol. 2. Thousand Oaks, CA: SAGE Publications, 1998: 59-63:71-73.

3. QSR NUD*IST 4 for Macintoshes. Qualitative Solutions & Research Pty. Ltd., 1997. (http://www.qsr.com.au)

4. Strauss A, Corbin J. *Basics of qualitative research*. 2nd Ed. Thousand Oaks, CA: SAGE Publications, 1998.

5. Patton MQ. Qualitative analysis and interpretation. In: *Qualitative evaluation and research methods*. 2nd ed. Newbury Park, CA: SAGE Publications, 1990:371-459

6. Miles MB, Huberman AM. Early steps in analysis. In: *Qualitative data analysis: an expanded sourcebook*. 2nd Ed. Thousand Oaks, CA: SAGE Publications, 1994:50-89.

7. Kruger RA. *Analyzing & Reporting Focus Group Results*. Focus Group Kit vol. 6. Thousand Oaks, CA: SAGE Publications, 1998.

8. Patton MQ. Enhancing the quality and credibility of qualitative analysis. In In: *Qualitative evaluation and research methods*. 2nd ed. Newbury Park, CA: SAGE Publications, 1990:460-506.

9. Guba EG, Lincoln YS. Judging the quality of fourth generation evaluation. In: *Fourth generation evaluation*. Newbury Park, CA: SAGE Publications, 1989:228-251.

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Appendix H

Tertiary Care Detailed Report

February 2003

prepared by
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EXECUTIVE SUMMARY

Findings are reported for three multidisciplinary, tertiary cancer care centre focus groups held in June and July 2002. The 27 participants were from 12 different health care disciplines reflecting the specialized, multifacted field of cancer care. There were 4 physicians (2 oncologists), 9 nurses and 14 other professionals. Groups were asked to discuss the role of their centres in relation to the districts and identify, using a nominal group process, the educational needs of health professionals working at the centres and in the community.

Methods of Analysis

Qualitative analysis methods were used. After transcripts were verified and imported into QSR NUD*IST 4 for data management, they were systemically coded. Data was reduced to meaningful units and assigned to categories. Comparisons were made within and between categories in the process of identifying and interpreting themes.

Key Findings

1. Tertiary Centre Roles

Three tertiary centre roles emerged as prominent themes in the data in all groups: providing, directing/guiding and ensuring up-to-date treatment; being a resource; and providing education.

Providing, directing and/or guiding, and ensuring up-to-date treatment. This appeared to be the central role. Support was evident for providing treatment closer to the patient's home, when feasible in terms of resources available in the community. The centre's role includes planning treatment and developing or providing protocols and clinical practice guidelines. Knowledge of clinical practice guidelines was a prominent educational need identified for the communities. Physician participants especially described a tertiary centre role in ensuring that up to date treatment is provided based on standards. For pediatric cancer care, participation in the Children's Oncology Network (COG), demands compliance with protocols. In one centre, a physician remarked,

> "I think too, maybe just expanding on what I said earlier, this really applies to all health professions. The most important thing about us a tertiary centre is that we see that optimal standards are applied uniformly across the province, and that 'just ain't happening.' "

Related to the central treatment role, were **resource and educational roles**. Participants expressed an overall willingness to serve as a treatment resource and provide education. It was recognized in all groups that communities or peripheral centres vary in their resources and capacity to provide treatment, and the centre's role will vary accordingly.

> "... some facilities are just going to use us as a [treatment] resource, and some facilities can be...educated more thoroughly. But they're not all equal."

There was also evidence expressed in a few groups of a **linking role**, related to the centre's overall treatment role. This involves connecting patients to care in their home community or other areas of the cancer treatment spectrum. Working relationships and communication appeared important in this regard.

2. Tertiary Centre Educational Needs

The most prominent educational need based only on the available discussion data appeared to be **keeping current** with cancer treatment. For the pediatric centre, maintaining COG membership was critical in this regard as COG provides access to the latest protocols. The role of *networking* to maintain current knowledge was prominent in a few groups, especially from the medical, nursing and pharmacy perspectives offered. A *broader knowledge base* about cancer care also was identified as a need by participants from several disciplines.

A complex, and not fully defined educational need emerged related to understanding aspects of **team work.** The data suggested this was an important, but somewhat diffuse theme.

> "I think the one very positive thing we could possibly do for ourselves, is that, as much as we espouse multidisciplinary team, interdisciplinary team, most places function loosely as a team, and I think we could do a whole lot around making nice, sharp, cohesive, very patient focused teams. I think we can do something about that."

Improved understanding of *other team members' roles and responsibilities* were discussed by participants. One multifaceted issue raised in the adult treatment centre groups was *clarity as to who is responsible for the patient's medical care. Communication* appeared to be an important aspect of team work. The IWK group offered the richest descriptive data concerning what is needed in communicating with the community, in the context of their espoused interdisciplinary model of care. Bi-directional communication, sharing information, and formalized communication channels were emphasized in this group. While saturation was not achieved, the data suggested that communication is both a systemic and educational issue. As one participant summarized, "what we really need to work on [is] on the communication channels and getting people to contact each other."

Other identified needs, less extensively discussed, included knowledge of *community resources* (most extensively discussed in the pediatric centre group in the context of multidisciplinary shared care model), *palliative care*, *patient communication* (conveying bad news and communicating with patients in end stages), *psychosocial, family and spiritual care.*

3. Community Educational Needs

Educational needs for professionals in the community focused in two areas, **treatment** and **knowledge of tertiary centre resources**.

In the **treatment** domain, participants emphasized knowledge of *clinical practice guidelines*, *chemotherapy*, *radiation*, and *pain & symptom management.*

> "But [another participant] is right, there needs to be more education around clinical practice guidelines for all disciplines and particularly, in cancer care best

> practices [...]. We said they needed to be shared more, there's not a lot of people [who] understand what clinical practice guidelines are, and what ones are out there governing practice..."

Educational needs pertaining to **pediatric treatment** were discussed in two groups, and needs related to chemotherapy and supporting children and families through the process were identified. Some participants raised that not all centres had the necessary teams in place to deal with pediatric cancer.

Regarding **tertiary centre resources**, the IWK's referral centre roles in diagnosis and treatment (COG participation) were stressed. A perception existed among some participants that physicians and nurses did not know what happens at the centre (e.g. radiation therapy). Participants across groups suggested several ways to promote and explain the centres' resources.

Other educational needs included *palliative care, spiritual care,* and *awareness of community resource*s (such as the Cancer Information Service).

4. Meeting Educational Needs

Groups variably explored meeting educational needs. Limited information was obtained on interdisciplinary education. Participants identified some means to reach out to the community, including strategies to increase awareness of the centre's resources, Telehealth and 'travelling teams' or 'road shows'.

A prominent theme across all groups was the **resource constraints** that participants and the community experience first hand, and affect continuing education by posing barriers to educational opportunities and involvement. Several examples of the interrelated time and human resource barriers were described by participants. One participant pointed out,

> "But without the time, and in order to have the time you need personnel, in order to have personnel, you need the money. So they all link together. If you have the money, personnel, time then a lot of the other educational issues, the follow up, the community care, the models we are talking about then fit into place."

5. Limitations

The qualitative findings are specific to the participants and groups involved and are not generalizable in the quantitative research sense.

Findings may not completely portray all themes or fully describe significant factors related to a specific topic. The range and depth of the data obtained was probably affected by the heterogeneity within and between groups. Homogeneity among participants is more likely to encourage uninhibited discussion. As well, the nominal group process tends to limit discussion and hence, the data available for qualitative analysis.

6. Conclusion

Within the limitations, the tertiary centre focus groups provided information to enrich an understanding of participants' perceptions of tertiary centre role, their own cancer educational needs and those of health care providers in the community.

For these participants, the central role appeared to be providing, directing/guiding and ensuring up to date cancer treatment. Associated with that role are important resource and educational roles. Linking the patient with the community is another aspect of the overall tertiary centre role.

Knowledge of up to date treatment is a perceived need for both tertiary centre and community providers. Aspects of team work, such as understanding roles and responsibilities and effective communication is an educational issue associated with delivering cancer care closer to patients' homes. This was particularly apparent in one group articulating a model of shared, interdisciplinary care. For community providers, knowledge of tertiary centre resources is another educational focus. A willingness to reach out to communities was evident among participants, though resource constraints are noted.

There were, however, significant interrelated time, human resource and funding resource barriers described by participants that affect educational involvement and opportunities.

FINDINGS

Findings are reported for three multidisciplinary focus groups held at each of the province's tertiary cancer care centres, in Halifax (QEII and IWK) and Cape Breton. Participants discussed the role of the centres in relation to the districts, and using a nominal group process identified the educational needs and priorities of health professionals working at the centres and in the community. Focus groups were approximately 1.5 – 1.75 hours in length, and were conducted by the same two co-facilitators, using a semi structured interview guide in June and July 2002.

1.0 Participants

A total of 27 health professionals from 12 different disciplines participated. Groups were of equal size, and were remarkable in their heterogeneity both within and between disciplines. Of the four physicians who participated, two identified themselves as oncologists. Nine participants were nurses with experience in a variety of oncology roles, including treatment and palliative care. There were 14 other participants from pharmacy, social work, dietetics, rehabilitation therapy, spiritual care and other specialized areas of cancer care delivery, coordination and administration. Heterogeneity was also evident among the groups. One group appeared to be composed of several members associated with care for a particular type of cancer, whereas this was not apparent in the other groups. One group did not contain an oncologist's perspective. Radiation, chemotherapy, pharmacy, administration, managerial and other specialized disciplinary perspectives were not similarly represented across groups.

2.0 Qualitative Analysis Methods

Qualitative analysis methods were used. Verbatim transcripts of the groups were verified, reviewed in their entirety, and imported into NUD*IST 4(1) for data management. Text was systematically coded, or broken down into meaningful units and assigned to categories. Categories were developed from the interview guide, the initial review of the whole transcripts, and as they emerged in coding. Categories were grouped, and themes were identified and interpreted, using a constant comparative approach (comparisons of data within and between categories).(2, 3, 4) Matrices were used to facilitate comparisons of categories and centres.(5) Consideration was given to (negative) cases that did not fit the patterns in the data.(6)

Measures to enhance trustworthiness of the findings were employed.(7) These included a systematic coding approach and an audit trail of transcripts, coding reports and matrices. Analysis was conducted by a person with a health and adult education background, who was sensitized to the emerging categories through previous analytical work on this project. Developing interpretations were checked and further refined through discussions with one facilitator.

3.0 Contextual Themes: Centres' Identifying Characteristics

While not a specific research question, two groups expressed what appeared to be salient features of their particular centres. These identifying characteristics seemed to be important contextual themes for the IWK and Cape Breton Centres. While an identifying characteristic theme was not detected in the third group, it is possible that direct exploration or another group configuration might have provided such data.

IWK Health Centre: A theme of *shared, interdisciplinary care* was often articulated in the IWK group. This explicitly-stated model of care appeared to underpin several discussions. Participants made frequent references to this model as they described their own and their teams' actions, interactions and attitudes. Discussions suggested a sensitivity to related teamwork communication issues (see Section 5.1.2).

Cape Breton Cancer Centre: "A *Beacon of Hope*" was how one participant described the centre wherein people may be treated close to home, rather than in Halifax. Participants communicated a sense of pride in this accomplishment, in a context where significant geographical and transportation barriers exist. Participants also appeared to perceive a close relationship and linkages with the community ("We are the community, our patients are our community…"). Overall, this group provided positive appraisals of the centre's characteristics. For example, a physician described receiving positive patient feedback regarding the time and attention received and access to other team members at the centre. Several participants described a unique hopeful, personal atmosphere filled with "humanity."

> "…I think that is a real positive point for our centre, is that it's very open, it's very homey, it says 'welcome' and it doesn't say 'institution', 'it doesn't say 'sick' and it doesn't say 'hospital.' "

4.0 Tertiary Cancer Care Centre Roles

Groups were asked to explore the role of the tertiary care centres in relation to the districts. In their discussions, participants often referred to the patient's home community, facility or centre, rather than 'district'. Their terminology is reflected in the presentation of the findings.

Three tertiary centre roles emerged as themes in the data in all groups: providing, directing or guiding, and ensuring up-to-date treatment; being a resource for the communities; and providing education. Another role, related to the centre's overall treatment role was linking patients with their home community or other parts of the treatment spectrum. This was explicitly expressed in two groups, with some implicit evidence present in the third group.

4.1 Providing, Directing or Guiding & Ensuring Up-to-Date Treatment

As some participants simply stated, providing cancer treatment is the major role for the tertiary centres. The goal of providing treatment closer to the patient's home appeared to be supported in all groups, when feasible in terms of the resources and expertise available in the community. In relation to the districts, participants expressed a central role in providing, directing / guiding, and ensuring up-to-date treatment for cancer patients.

Across all groups an important role was *directing or guiding treatment* through the providing and/or setting treatment plans, protocols, and/or clinical practice guidelines. As well, an oncologist identified provision of periodic clinic visits to peripheral areas as another aspect of the treatment role.

In relation to the districts, there were some participants in two groups who described aspects of a tertiary centre role in *ensuring that up to date treatment is provided.* This was expressed not only by oncologists, but by this non physician who said,

> "We have a role in making sure that everyone who comes down with cancer in the province has good care and that they have a feeling that they've had the best chance they could possibly get."

Physician participants emphasized the centres' role in assuring that optimal standards are applied. As stressed in the IWK group, participation in the Children's Oncology Network (which provides access to the latest protocols) demands this. The centres were perceived by some to have a role in identifying whether the community can "take over the care". Knowledge of the community's resources and their capacity to provide treatment, and the application of standards are necessary in this regard.

> "I think too, maybe just expanding on what I said earlier, this really applies to all health professionals. The most important thing about us as a tertiary care centre is that we see that optimal standards are applied uniformly across the province, and that 'just ain't happening' " . (physician)

4.2 Being a Resource for Communities

There was a 'willingness' expressed by participants across groups and in several disciplines, for the tertiary centres to serve as a treatment resource for health care providers in the communities.

> "One thing I think that we need to increase knowledge of the communities of available resources that are here, and that we're not perceived of as the ivory tower, cause I've heard that at times, so that we're perceived as just willing to share and work with the community and to best enable care for the patient and family."

It was expressed in all groups that communities or peripheral centers vary in their resources and capacity to provide treatment. It was also explained that the center's role as a resource for treatment will vary accordingly, from provision of specific treatments to guidance and consultation.

> "Some facilities are just going to have to use us a [treatment] resource, and some facilities can be [...] educated more thoroughly. But they're not all equal".

Fulfilling this role will require resources, as some participants observed. Dialogue from one group, presented below, illustrates concerns about having adequate resources to simultaneously provide patient care at the centre and respond as a resource. Similarly, in another group, questions were raised about financing 'travelling teams' to fulfill an educational role.

> "Communities, we want them to see us as a resource, and if they're having all these questions and we still have to take care of children at this centre, how do we do that? How do we take care of the kids that we have and still be a resource to the centres out there?

> Another participant added, "And then it comes back to the human resource issue. You have the patients in front of you, how do you take care of them? How do you respond to all those questions and answer appropriately that you can give them the guidance and support they need?"

4.3 Education

Another tertiary centre role expressed in all groups was education of health professionals in the community (as expected given the purpose of the group). Sharing treatment plans, protocols, and/or clinical practice guidelines was one focus. One group identified education could not be standardized, but would vary according to the available community or facility resources and specific needs. Tertiary centre participation in education included both formal educational programs (e.g. chemotherapy programs, travelling 'road shows') and informal education, implicit in communicating patients' treatment plans, and serving as consultative resources concerning patients' problems.

4.4 Linking & Liaison

There was some evidence the tertiary centre was also perceived to have a linking and/or liaison role. The patient's 'stop' at the centre was likened to a 'stepping stone' in a river by one participant. Patients are returned to the home community for care, or move to another part of the cancer care spectrum, requiring that linkages be made to the next 'stop'. Another participant described the role as "...providing some sort of liaison connection that way." Linking involves establishing and maintaining a working relationship with other professionals focused on patient care, and this requires communication. Communication needs with respect to teamwork were most extensively outlined by the IWK group (see section 5.1.2). It was also suggested that the IWK be represented on each district cancer care committee to facilitate liaison work, though another participant expressed doubt this would occur given resource constraints.

5.0 Educational Needs

Groups were asked to identify and priorize educational needs for tertiary and community personnel through a nominal group process (analyzed separately by others). Although some limitations are present (see section 7.0), the qualitative data gathered as part of the process were analyzed, to enrich the understanding of the expressed needs. Some groups explored some areas more than others, and the depth of descriptive data varied. Saturation(2) was unlikely.

5.1.0 Tertiary Centre Educational Needs

The most prominent educational need, based on the discussion data, appeared to be keeping current with cancer treatment. For the pediatric centre, maintaining COG membership was critical in this regard. The role of networking to maintain current knowledge was prominent in a few groups, especially from the medical, nursing and pharmacy perspectives offered. A broader knowledge base about cancer care was identified as a need by participants from several disciplines.

A complex, not fully defined educational need emerged related to understanding aspects of team work. The data suggested this was an important, but somewhat diffuse theme. The need for an improved understanding of other team members' roles and responsibilities was discussed by some participants. One issue raised in the adult treatment centre groups was clarity as to who is responsible for the patient's medical care. Communication appeared to be perceived by some as an important aspect of the team work and working relationships. The IWK group, in the context of their espoused interdisciplinary model of care, offered the richest descriptive data concerning what is needed in communicating with the community. Bi-directional communication, sharing, and formalized communication channels were emphasized in this group. Overall, data suggested that communication is both a systemic and educational issue.

Less extensively discussed identified needs included knowledge of community resources, palliative care, patient communication, psychosocial, family and spiritual care.

5.1.1 Cancer Treatment: Keeping Current

The three groups generally expressed a need to have up-to-date knowledge of cancer treatment knowledge and maintain clinical expertise.

Pediatric Cancer Treatment:

To remain updated, the IWK group stressed the importance of maintaining membership in the Children's Oncology Group (COG) as it functions as their standard of care and provides access to the latest protocols. Institutional support to continue to attend meetings that enabled networking with other COG members.

Networking:

The role of networking to maintain current knowledge was highlighted in a few groups, and is discussed in more detail in section 6.2.

Broader Knowledge Base:

Nursing, social work, pharmacy and therapy perspectives in one group contributed that a broader knowledge base of the oncology treatment spectrum would be useful in patient care. Discussion suggested this need encompassed both tertiary care and community providers.

Grand rounds, were an "overall good review for people in oncology to learn about the disease, disease process, and what's the current treatment," according to a nurse participant. Observational experiences or nursing staff exchanges in other cancer treatment areas were also suggested to broaden the knowledge base.

Feedback to the centres about how patients are doing once their treatment is completed was another information need expressed by non physician personnel in an adult treatment centre, who wished to know how the patient is doing, in part to balance their own perspectives of the treatment spectrum and outcomes in cancer care.

Specific Educational Needs:

Detailed information on educational needs related to maintaining clinical expertise was not systematically obtained. Some individuals cited specific educational needs (nutritional assessment, psychotherapeutic counselling techniques, and lymphaedema prevention and treatment), that pertained to their own discipline or their focus on treating particular cancers. Further exploration is necessary to obtain a complete understanding of discipline-specific needs.

5.1.2 Team Work: Roles, Responsibilities & Communication

A better understanding of teamwork, including others' roles and responsibilities and effective communication was another educational issue expressed among the groups.

While it was not always clear if participants were referring to tertiary centre teams or larger teams that encompassed the community providers, the nature of the concepts themselves suggested the needs may be applicable to both entities.

The data suggested teamwork and its related issues were an important, but somewhat diffuse theme. Saturation(2) was not achieved in the analytic categories. While more direct exploration of these issues might yield additional perspectives, the findings below suggest a complex educational (but potentially rewarding) challenge.

> This nurse remarked,
>
> "I think the one very positive thing we could possibly do for ourselves, is that, as much as we espouse multidisciplinary team, interdisciplinary team, most places function loosely as a team, and I think we could do a whole lot around making nice, sharp, cohesive, very patient focused teams. I think we can do something about that."

Roles & Responsibilities:

Understanding other team members' disciplinary roles and responsibilities was a need articulated in two groups. This knowledge was perceived to be important for facilitating patient care in terms of knowing "who the resources are" within some participants' own institution and/or in the community. For example, radiation therapists with frequent, ongoing patient contact might identify problems and refer patients to other team members for assistance, if they were more knowledgeable about others' roles and responsibilities.

Some participants noted a lack of clarity as to who has responsibility for the patient's care. This was raised in the two adult treatment centre groups, and communication may be one contributing factor. Information as to who has responsibility for care may not always be adequately communicated to team members or to the patient, as the following comments help illustrate:

> "And for the patients to know who is directing their care when they leave here, and I mean hopefully the physicians that occurs on their last visit. Who is sort of you know, the main coach in your care? Like is it going to be your family physician, palliative care, cancer centre doctor, like who do you call?"
>
> This same participant further described, "A lot of times we are getting calls when it should be the family doctor and I think people just don't know who's doing what."

Further, there was a perceived reluctance on the part of family physicians in some instances to reassume care. An array of reasons were offered by both physician and non physician participants in one adult centre group. These included: physicians may feel intimidated related to their lack of knowledge; there are complex issues of patient "ownership; " sometimes family physicians may assume someone else has responsibility once referral is made; and there is inadequate reimbursement for dealing with time consuming problems.

The limited data available suggested that clarifying and understanding roles and responsibilities in patient care is a multifaceted issue. Interestingly, clarity was not raised as a problem in the IWK group, which also described explicit communication between the centre's team members and professionals in the community. While further exploration and contextual information would be required to draw any inferences, this participants' comments concerning proactive, formalized communication are noted:

> "And then obviously with each child that's diagnosed, that you know your formal contacts are going to be made, depending on where they are. And then, that's laid out pretty, pretty specifically; but we have built that into what we do and our model of care as an interdisciplinary model."

Communication

Participants were not directly asked to explore communication issues. Different groups described different elements of communication in cancer care, and discussions indicated several participants viewed communication as a significant factor in partnership or collaborative relationships with the community-based professionals. Some participants expressed that communication skills are an educational need.

Communication was a prominent theme in the IWK group. In the context of the interdisciplinary shared care model, participants at the IWK described several aspects of communication needed in the working relationships with the communities. There was an emphasis on "bi-directional" communication; linking with communities about COG and individual patients' care; "passing on" treatment plans; and establishing and maintaining channels of communication, usually discipline to discipline. This group also commented on the need to time communication of information appropriately so as not to overwhelm, but yet help other health care providers anticipate possible patient problems. Some IWK participants noted that going to the patient's home community, perceived to be an effective communication, education and relationship building strategy, was not possible with resource constraints. "One of the suggestions that [another participant] talked about, going to hospitals, it was something that was done quite a bit, but we can't do it. We don't have the resources anymore."

Problems with some communication channels were noted in other groups (e.g. family physicians not reading dictated notes; information not quickly available when responding to calls from palliative care patients at home.

Overall, data indicated that communication is both a systemic and educational issue. As one participant summarized, "what we really need to work on [is] on the communication channels and getting people to contact each other."

5.1.3 Community Resources

Knowledge of community resources to facilitate patient and/or family access to supports (e.g. financial and psychosocial) was another tertiary centre educational need, expressed in two groups. The importance of this need was most extensively discussed in the IWK group in the context of shared interdisciplinary care. This group also noted that sometimes supports or resources are assumed to exist when they in fact do not, and that advocacy for pediatric resources is needed.

5.1.4 Palliative Care

Palliative care as raised as an educational need for professionals working in both adult and pediatric tertiary and community cancer care. Pain and symptom management, physical comfort, spiritual and psychosocial care were the components identified among the three groups.

5.1.5 Patient Communication

One group explored in more detail patient communication as an educational need. While viewed as relevant to all aspects of cancer care across several disciplines, some participants noted a particular need for improved skills communicating "bad news" and when interacting with the patients who are nearer the end stages.

> "Like now a lot of our patients are being treated almost until they are dying, where before they were stopping their treatment at a certain phase and they were just coming in for check ups and things like that. So I just thought, more communication when they're getting near the end stage [...]
>
> ...just what to say to people [...], more education because we're seeing them." (nurse manager)

5.1.6 Psychosocial Care

Educational needs with respect to psychosocial care were also raised, but were not described in detail. There was a perceived need for information about patient support resources, and for those offering counselling, information on psychotherapeutic techniques used with cancer patients.

5.1.7 Family Care

Concern for families facing the stresses posed by pediatric cancer was often expressed in the IWK group discussions. Psychosocial care of the family, improving family assessment and understanding more about the impact on families, siblings and adolescents were specifically mentioned educational needs. Mention was also made of recognizing caregiver stress in another group, but it was not explored further.

> "I think it's a bit about a what [participant ****] said, is just our ability to do fairly good family assessments, and by that, ...recognizing when families are managing with that care that we're asking them to do and when sometimes they may in fact not; and then, how we manage, or help families; support them.

> Because I think it is very easy to keep saying this needs to be done without adequately assessing just what is possible out there in the homes." (IWK participant)

5.1.8 Spiritual Care

Chaplains in two groups highlighted the importance of meeting patients' spiritual care needs through recognizing spiritual issues, understanding and using spiritual care resources. They identified the role of spiritual care as an educational need for both tertiary care and community providers.

> "…it's meaning stuff, 'what does it mean for my life when I've heard this news?' That's spiritual stuff.'

> "So if a person is feeling despair to think, 'yes, this is a spiritual issue. If they're experiencing shock, then to speak not only with a nurse specialist, but the chaplain."

5.2.0 Community / District Educational Needs

Educational needs for professionals in the community focused in two areas, treatment and knowledge of tertiary centre resources. In the treatment domain, participants emphasized knowledge of clinical practice guidelines, chemotherapy, radiation, and pain & symptom management. Regarding tertiary centre resources, the IWK's referral centre role in diagnosis and treatment (COG) were stressed. Participants across groups suggested several means of familiarizing community-based professionals with their centres.

Other identified educational needs less extensively discussed included palliative care, and spiritual care, and awareness of community resources such as the Cancer Information Service.

5.2.1 Cancer Treatment

Educational needs with respect to cancer treatment in the community were identified in the following areas: clinical practice guidelines and/or protocols, chemotherapy, pain and symptom management, radiation therapy, and knowledge of tertiary centre resources. Specific pediatric needs were also identified

Clinical practice guidelines and protocols:

In each group, clinical practice guidelines, or in the case of the IWK, COG standards and protocols, were clearly identified as the foundation for treatment and were an important educational need.

> "But [Participant ****] is right, there needs to be more education around clinical practice guidelines for all disciplines and particularly, in cancer care best practices […]. We said they needed to be shared more, there's not a lot of people [who] understand what clinical practice guidelines are, and what ones are out there governing practice…"

> "…the Children's Oncology Group is an international organization of pretty well all centres that take care of children with cancer within North America and a few outside. So that's kind of our standard of clinical care, our participation. So, its advantage is that we have access to the latest care, but it also has a burden of expectation [for] the community as well as ourselves for data and monitoring, and certain rigidity and compliance with treatment protocol. So, we are, that has become more and more of an issue as we get more and more patients and they're spread out more. So we are going to undertake an education endeavour specifically related to explaining to the communities, centers, the importance of the meaning of COG participation." (physician)

Chemotherapy & Radiation Therapy:

Physicians (family & emergency), nurses, and pharmacists (hospital & retail) were perceived to have educational needs related to chemotherapy and management of side effects.

> "Family physicians, if they had some kind of course or something to take. Like I have a lot that I work with that are asking me questions; it should be me asking them questions and getting answers." (nurse)

Both centres offering radiation therapy identified knowledge of this treatment as an educational need of providers in the community (including inpatient staff in Cape Breton).

> "There needs to be a thrust in radiation therapy; why we give it, how we give it, how much is enough, and the care of patients who receive radiation therapy." (a manager)

Some participants described how distressing it is for patients when they are misinformed about the radiation treatment process by their family physician, as this participant's comments indicated:

> "…a lot of patients come to us with ideas that are wrong. The family physician has told them that, you know, you're going to have five treatments, but they're having thirty five. It's quite a process for them and it is really anxiety ridden. If physicians had the proper information, then the patients would have a better ability to cope with what we're going to put them through.[…] because if you set them down the wrong garden path they hold onto that for all their worth and they won't forget it. They're very emotional when you tell them anything that is different than what their GP or whoever else has discussed with them. It's very difficult." (radiation therapist)

Pain & Symptom Management

In two groups, participants articulated educational needs for physicians and nurses with respect to pain and symptom management including, but not restricted to palliative care.

> "[Nurse participant's name] you were there,…there was a patient anyway, right here, a patient who had pain and according to the patient, no one knows, she said her physician told her [not] a narcotic because they cause constipation. So

> the poor patient, screaming all day of pain and then cannot take a narcotic because of constipation. Other nurses, you now when I order morphine and stuff like that, they look at me, 'what about the respiration, you're going to kill the patient.' " (physician)

One participant noted that the tertiary centre receives calls from patients using the specialists as family physicians, taking time away from "what they're supposed to be doing". This person also advocated "enhancing the role of the family physician in pain and symptom management."

5.2.2 Pediatric Cancer Treatment in the Community

COG was described as the "lynch pin" in the treatment of pediatric cancer, and as it provides the standard of care, is an important educational focus.

Most patients served by the Cape Breton Cancer Centre are adults. Participants in Cape Breton expressed that treating their pediatric patients (n=10) was different from adults, especially their chemotherapy and the "intensity" of the care they required. These presented "a whole realm of educational issues" that were not fully explored in the group. The pediatric care educational needs of professionals in community sites were further defined by the IWK group and included pediatric pharmacology as well as how to "work with families whose children are ill, and specifically how to support children through the therapies as well." Other specific needs included knowing what to expect when the patient returns home, anticipating what problems may arise, dealing with basic oncological emergencies, and recognizing when the patient needs to come back to the tertiary centre.

5.2.3 Tertiary Centre Resources

Across groups, an increased awareness and understanding of tertiary centre resources was an identified educational need of professionals outside the centre, particularly physicians and nurses.

In pediatric cancer care, the use of the IWK as a referral centre was emphasized for 1) diagnosis with its specialized expertise and ancillary studies (important since diagnosis is the foundation for treatment), 2) treatment as part of the Children's Oncology Network, and 3) as a "back up" resource.

Participants communicated an awareness that professionals did not always know what happens at the centre (e.g. radiation therapy), and they expressed considerable interest in helping them become more familiar with the centre. Ways suggested to increase awareness included: practicums or specific educational experiences (e.g. chemotherapy), open houses, virtual tours, videos and pdf pamphlets. Some participants indicated some resources were presently under development.

5.2.4 Community Resources

One group identified improved knowledge about other supportive resources, such as those offered by the Canadian Cancer Society, as an educational need. Community-based providers could help their patients access resources earlier in treatment, receive information, and experience less anxiety. It was suggested that specialists, as well as family physicians should be encouraged to promote patient use of the toll free Cancer Information Service, since some patients may not return to the family physician before their contact with the centre.

> " I think that people outside this area also have to know what other services are available for the patient before they get here. What the Cancer Society can set up for them, that type of thing, and that in itself will relieve a lot of anxiety on the patient's behalf. They shouldn't have to wait until they get to Halifax to talk to our representative; there are representatives everywhere and those things should be dealt with before they come to us. It would just make everything flow a little bit smoother I would think."

5.2.5 Palliative Care

This educational need was raised, but not discussed in depth (reported in section 5.1.4).

5.2.6 Spiritual Care

The role of spiritual care was another identified need for providers both inside and outside the centre (section 5.1.8).

6.0 Meeting Educational Needs

Groups variably explored meeting educational needs. The limited information available on interdisciplinary education suggested participants had encountered both positive and negative attitudes and experiences. Networking (associated with conferences) appeared to be a prominent strategy to keep up-to-date. Two strategies to reach out to the community included Telehealth and travelling teams or road shows. Telehealth has some limitations with respect to convenience, reception, and networking potential.

The most prominent theme in meeting educational needs was the resource constraints that participants and the community experience first hand, and affect educational opportunities.

6.1 Interdisciplinary Education

Interdisciplinary education was not addressed directly by the groups, but some discussions contained interdisciplinary content. The limited data suggested there were both positive and negative experiences with interdisciplinary education. Sharing conferences and other educational opportunities was discussed in very positive terms across disciplines in one group. e.g. "It's also a good thing for us a team." Attending oncology grand rounds helped meet the information needs of some nurse participants, who indicated other disciplines could also benefit, particularly if the presentation was adjusted to make content more easily understood. Discussion also indicated attitudinal barriers are sometimes encountered with respect to including non physicians in physician oriented events.

6.2 Networking

Networking to keep current was prominent in two groups and across disciplines. The IWK group emphasized networking with other COG members. There was also some interest expressed in the IWK group in exchanging experiences and approaches with adult cancer treatment providers. The Cape Breton group advocated sharing among other treatment centres, especially with respect to practice guidelines. This group suggested a regular continuing education opportunity with their Halifax counterparts (such as a symposium), possibly rotating the location.

> "I think everything has to be shared around the province, all sites, and we all have to do that, become more efficient and effective." (nurse manager)

The following comments illustrate concerns that reduced education budgets will reduce opportunities to network, which serves as an important means to update knowledge about treatment and resources.

> "...when budgets are being cut, they seem to cut the ability to be able to network, and it's essential that individuals are able to network, and that networking provides often time essential contact for work that's being done in the hospital as well as update individuals on a day-to-day basis..." (physician)

> "...sometimes local conferences and networking -- you start to see channels that you never knew existed, and that is [...] the benefit. And that is one of the things that does get cut is conferences and the education, but that's the part that opens up those networks and makes you increase your awareness." (nurse)

6.3 Reaching Community Professionals

Ways to reach out to the community professionals, in addition to the strategies mentioned in section 5.2.3, included 'travelling teams' or 'road shows' and Telehealth.

Travelling teams: 'Travelling teams' or 'travelling road shows' were discussed in all three groups as a means to provide education in the communities, though there are resource considerations in terms of staffing and financing such an initiative.

Telehealth/Videoconferencing
Telehealth was raised as a means to provide education and to facilitate transfer of patient care to the community. However, some limitations were cited and included: frustrating, poor quality reception and inconvenient times and locations. As well, it was suggested that Telehealth does not meet the learner's need to network with the educator in the same way as face to face conferencing. Similarly, the IWK group noted with cutbacks, there is now less travel to the patients' home community, and some interest was expressed in evaluating direct contact and Telehealth transfer.

6.4 Resource Barriers

A prominent theme across all groups was the significant and interrelated time, human resource, and funding systemic barriers that affect continuing education.

Participants described the impacts of human resource constraints on their own and the community professionals' involvement in education. For example, rural Cape Breton nurses were willing, but unable to attend a chemotherapy course offered by the Centre because there were no staff to relieve them. No relief coverage revents a chemotherapy nurse from attending videoconferences. Short staffing is also an issue at the tertiary centres. One focus group did not contain an inpatient nurse because of staffing constraints. Staff shortages and heavy workloads in radiation therapy means continuing education is obtained on personal time.

Funding for education was another concern. With respect to personal education, some participants indicated their departments have no education budget, and others feared losing educational and networking opportunities with more cut backs. Burn out may be one reason why staff are not applying to go to opportunities even when funds are available.

Concerning community education, travelling to communities to provide education was supported, but there were questions raised in two groups about resources to do this. While more direct contact may be needed, with present resource constraints there is now is less travel by IWK personnel to communities to provide education about a patient's care.

Cancer Care Nova Scotia (CCNS) has "a big responsibility" in helping to accomplish the community education, voiced one participant concerned about resource issues.

The funding, time and human resource barriers are interrelated, and as articulated by this participant, impact not only education, but implementing the proposed model of care.

> "But without the time, and in order to have the time you need personnel, in order to have personnel, you need the money. So they all link together. If you have the money, personnel, time then a lot of the other educational issues, the follow up, the community care, the models we are talking about then fit into place." (physician)

7.0 Limitations

- The qualitative findings are specific to the participants and groups involved and are not generalizable in the quantitative research sense.
- Findings may not completely portray all themes or significant factors related to a specific topic. Breadth and depth of discussions varied across groups, and may have been influenced by two departures from typical focus group methods.

Group heterogeneity: Focus groups typically are homogeneous in composition to facilitate uninhibited discussion.(7) The heterogeneous group composition used in this study offered the advantage of including as many disciplinary perspectives as possible, appropriately reflecting the multifacted and specialized nature of cancer care. Paradoxically, heterogeneity also must be considered as a factor possibly limiting the depth of discussion and range of perspectives obtained. For example, participants may not have disclosed their own learning needs in front of supervisors or coworkers, and participants may have withheld views that were contrary to those with different status, power and authority in the workplace. Heterogeneity between groups may have also limited the extent themes could be identified and described. A large number of disciplinary perspectives were present overall, but dispersed variably among the groups, affecting the comparisons that can be made in the analytic process.

Nominal group process: Focus groups are not typically working or decision making groups.(7) In this research, a nominal group process was used to identify educational needs and priorities (analyzed separately). The nature of the nominal group process limits discussion, contrary to the usual focus group approach. Therefore, the amount of descriptive data available for analysis of the educational needs questions was limited. Data concerning the role of the centres was collected using more usual focus group procedures.

8.0 Conclusion

Within the limitations, the tertiary centre focus groups provided information to enrich an understanding of participants' perceptions of tertiary centre role, their own cancer educational needs and those of health care providers in the community.

For these participants, the central role appeared to be providing, directing/guiding and ensuring up-to-date cancer treatment. Associated with that role are important resource and educational roles. Linking the patient with the community is another aspect of the overall tertiary centre role.

Knowledge of up-to-date treatment is a perceived need for both tertiary centre and community providers. Aspects of team work, such as understanding roles and responsibilities and effective communication is an educational issue associated with delivering cancer care closer to patients' homes. This was particularly apparent in one group articulating a model of shared, interdisciplinary care. For community providers, knowledge of tertiary centre resources is another educational focus. A willingness to reach out to communities was evident among participants, though resource constraints are noted.

There were, however, significant interrelated time, human resource and funding resource barriers described by participants that affect educational involvement and opportunities.

9.0 References

1. NUD*IST 4 for Macintoshes. Qualitative Solutions & Research Pty. Ltd., 1997. (http://www.qsr.com.au)

2. Strauss A, Corbin J. *Basics of qualitative research.* 2nd Ed. Thousand Oaks, CA: SAGE Publications, 1998.

3. Patton MQ. Qualitative analysis and interpretation. In: *Qualitative evaluation and research methods.* 2nd ed. Newbury Park, CA: SAGE Publications, 1990:371-459

4. Miles MB, Huberman AM. Early steps in analysis. In: *Qualitative data analysis: an expanded sourcebook.* 2nd Ed. Thousand Oaks, CA: SAGE Publications, 1994:50-89.

5. Kruger RA. *Analyzing & Reporting Focus Group Results.* Focus Group Kit vol. 6. Thousand Oaks, CA: SAGE Publications, 1998.

6. Patton MQ. Enhancing the quality and credibility of qualitative analysis. In In: *Qualitative evaluation and research methods.* 2nd ed. Newbury Park, CA: SAGE Publications, 1990:460-506.

7. Guba EG, Lincoln YS. Judging the quality of fourth generation evaluation. In: *Fourth generation evaluation.* Newbury Park, CA: SAGE Publications, 1989:228-251.

8. Morgan DL. *Planning focus groups.* Focus Group Kit vol. 2. Thousand Oaks, CA: SAGE Publications, 1998.

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